

Final report

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Dementia dogs: Their impact on community-dwelling persons with mild to moderate dementia and their caregiver.

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Rationale for the study

Dementia refers to a set of symptoms caused by neurocognitive disorders that progressively interfere with a person's ability to perform activities of daily living. Symptoms can include loss of memory, problem-solving, or language, as well as changes in mood or behaviour. It is estimated that 1.1 million Canadians are directly or indirectly affected by the disease. Currently, 564,000 Canadians live with dementia, 16,000 of whom are under the age of 65; with 25,000 new cases of dementia diagnosed annually (Alzheimer Society of Canada, 2016), this number is anticipated to increase to 937,000 within 15 years (Alzheimer Society of Canada, 2016). Family caregivers are often relied upon to help individuals with dementia to manage sleep deficiency (McCurry et al. 2006), remain active, connected to their communities (Eales et al. 2015), and safe amidst declining cognition and functional abilities.

In Canada, the estimated annual cost of dementia is 10.4 billion dollars (Alzheimer Society of Canada, 2016) and of unpaid caregiving is \$25 billion (Hollander et al. 2009). A 2012 survey (Sinha 2012) found that, of the 8.1 million Canadian carers (28% of population), 44% were between the ages of 45 and 64 years, 10% provided more than 30 h of support a week and 60% continued to work while providing care. Furthermore, approximately 50% of family caregivers cared for seniors with health conditions (Turner and Findlay 2012) and close to half a million supported a person with dementia (Eales et al. 2015). The overwhelming majority of caregivers (89 %) offered support for a minimum of one year, with 50 % doing so for at least four years (Sinha 2012).

Supporting family caregivers is a national public health priority given their essential role in the healthcare system (Hollander et al. 2009) as acknowledged in the Health Council of Canada's (Kitts 2012) "seniors in need, caregivers in distress" report. Caregivers, however, require support to foster resilience and ensure that they can continue to provide care while maintaining their own wellbeing. Despite the majority of caregivers reportedly being in good, very good, or excellent physical and mental health, caring can take its toll and be burdensome (Butler-Jones 2010; Eales et al. 2015; Kitts 2012; Sinha 2012). Caregivers are at increased risk of physical, emotional, and financial burden if: (1) they provide more than 21 h per week of care; (2) care for persons with depression, cognitive decline, behavioural change; or (3) care for persons with terminal conditions (Butler-Jones 2010; Canadian Institutes of Health 2009; Kitts 2012; Hollander 2009; Sinha 2012). Stress can result in health challenges, social isolation, loss of income, and family conflict (Dumont et al. 2009; Kitts 2012; Stajduhar et al. 2010). The strain on family caregivers is anticipated to intensify given the aging population (Dudgeon 2010; Eales et al. 2015; Smetanin et al.

2010). Hopefully, canine assistance may help. Enthusiastic testimonies and anecdotes on the use of dementia dogs can be found on their websites, and those of others about neuro service dog (Wilderwood Service Dogs, 2022). Anecdotal evidence come from 6 dog training schools in the world and this study was put in place to measure their impacts on the life of caregivers and persons living with dementia living together.

Main goal, objectives and hypotheses

The present research proposal was initiated by Bernie Travis, caregiver and founder of Early Onset Dementia Alberta (EODA), who observed home support being provided by companion dogs paired with persons living with dementia. The **main goal** of this present project was design to examine how dementia dogs may support family caregivers and persons with dementia.

The **objectives** were to:

1. To examine the impacts of canine assistance on both the person with dementia and their caregiver (e.g., engagement, socialization, well-being, activity levels, wandering, meaning and purpose, quality of life, stress, health, engagement, and economic impact).
2. To examine the acceptance of canine assistance in public places in the prior 3 months (e.g. approachability situations, socialization experiences).
3. To conduct a cost-effectiveness analysis associated with having canine assistance in the home of the community-dwelling person with dementia (e.g., costs related to dog acquisition/training, post-placement, costs savings; benefits measured in terms of quality of life for carers and those with dementia).
4. To characterize the physical activity level around the home and sleep efficiency during 7 consecutive days of persons with mild and moderate dementia (e.g. frequency of walking).

Hypotheses [H] were proposed:

[H1] The presence of a neuro service dog or companion dog positively impact both the person with dementia and his/her caregiver (e.g., evidence of improved engagement, socialization, etc.).

[H2] The presence of a companion dog or a certified dementia dog with a person with dementia will result in the person with dementia being more frequently approached, and experiencing increased occasions of social engagement.

[H3] Neuro service dogs are a cost-effective, value added alternative (i.e. additional benefits in terms of quality of life outweigh additional costs) relative to companion dogs, and companion dogs are a cost-effective alternative relative to having no dog.

[H4] The level of exercise and the quality of sleep are better with a companion dog or a certified dementia dog than without a dog.

Methods

A **comparative case study** research design will be used to address objectives and test our hypotheses. This type of design is relevant when knowledge is unavailable and scientific evidence of level 1 quality (i.e., exploratory) (Fortin & Gagnon, 2015). To answer our research question, we will compare three data set collected using the following methods: phone interviews and qualitative thematic analysis, cost-benefit analysis, and activity monitoring. Each of 3 case studies will be comprised of a caregiver, a person with mild to moderate dementia, and either (1) a neuro service dog, (2) a companion dog, or (3) no dog.

Case 1 included 28 companion dogs and caregiver/person with dementia pairs. Recruitment was done with the help of Alzheimer and Caregiver associations.

Case 2 included 5 neuro service dogs and caregiver/person with dementia pairs. The phone recruitment was done by the intermediary of Wilderwood Service dogs.

Case 3 included no dog but 23 caregiver/persons with dementia pairs. At the beginning the recruitment strategy was similar than the one for people with a companion dog but because it was not attracting participants we had to access the Quebec rehabilitation center archives to contact people directly people that may have dementia.

Selection criteria: 1-Caregivers had a canine assistance for more than one year. 2-Caregivers agreed to discuss their experience of having a canine assistance or their reasons why they did not have a dog. 3- Persons with dementia were community-dwelling, seeing the caregiver every day, and 4- had a mild or moderate stage of dementia.

Data collection

Data were collected through 45-60 minutes telephone interviews that included completion of the Caregiver's Burden Scale and sociodemographic questions. A pre-tested interview guide was followed (see appendix 1 for full English and French copies). Interviews were conducted by co-authors FD (n=32),

AR (n=20) and MR (n=4). Data collection began in 2018 and concluded in December 2021. Participants were reached by various partners (Alzheimer society of Canada and its provincial branches, caregivers organizations, CenterWatch (USA) and the CIUSSS de la Capitale-Nationale) using an informational poster (see appendix 2). Potential participants reached us directly and were presented with the consent form (see appendix 3). Recordings of the interviews were manually transcribed by students in psychology (n=21) or occupational therapy (n=9), and by co-authors (AR n=20, MR n=4, and FD n=2).

The phone interview guide was based on one used for veterans with PTSD who had a service dog (Lessard et al., 2018). The phone call was done with the caregiver, and with the person with dementia if possible. The person with dementia joined the caregiver at the beginning of the interview when talking about the dog's roles and tasks. Questions addressed 4 topics: 1) The use of the dog in rural or urban contexts (reasons for use, tasks, and activities), frequency of use, and intensity of use. If no dog: the participant was asked: "Why do you want a dog or why not?"; 2) Advantages with the use of the dog; 3) Disadvantages, inconveniences, or obstacles with the use of the dog. If no dog, "what are the expected advantages and disadvantages of having a dog?"; and 4) Recommendations for the maintenance of the NSD program in the future. There were only 2 questions for the person with dementia: 1) What do you do with your dog? 2) And what is your dog doing for you?

The Caregiver's Burden Scale (CBS) was completed at the end of the phone interview. This questionnaire measures the perception that caregivers have of their partner's capabilities and the burden on caregivers (Dumont et al. 2008). The perception of capabilities was comprised of five questions about what daily activities or mobility the person with dementia can accomplish. The 16-item scale (of burden) asks caregivers to circle the score that best reflects their situation on a 4-points scale from Not at all to Very Often. A higher score suggests a stronger burden on the caregiver. In the Dumont et al. study of 167 participants, the questionnaire was shown to have high internal consistency (Cronbach's alpha=0.95), good construct validity as items were associated to the two predicted factors (61% of the variance explained, with a KMO of 0.93), and convergent validity showed good correlations to other questionnaires.

An economic analysis was conducted using online questionnaires (15 minutes) in the days following the interview. These included the ICECAP-O (Grewal, 2006), the ASCOT-SCRQoL (Malley, 2012), and a cost questionnaire, the Resource Utilization in Dementia (RUD 3.2) questionnaire (Wimo et al 1998).

The ICECAP-O (ICEpop CAPability measure for Older people) is a measure of capability in older people for use in economic evaluation. The ICECAP-O focuses on wellbeing defined in a broader sense. It comprises five attributes Attachment, Security, Role, Enjoyment and Control.

The ASCOT-SCRQoL (Adult Social Care Outcomes Toolkit measure of Social Care-Related Quality of Life) includes a preference-weighted measure of social care-related quality of life for use in economic evaluations. ASCOT has eight attributes: personal cleanliness and comfort, food and drink, control over daily life, personal safety, accommodation cleanliness and comfort, social participation and involvement, occupation and dignity.

The Resource Utilization in Dementia (RUD) questionnaire measures healthcare resource utilization among older adults with dementia and their caregivers, and time spent on formal and informal care by caregivers.

At the end of the phone interview, the research coordinator asked the caregiver about monitoring of the person with dementia's physical activity using an actimeter (ActiGraph's GT3X-BT) attached to the person's wrist for 7 consecutive days. It was then mailed to them (including instructions, a log sheet and a prepaid envelop) and had to be returned to the research team following data collection.

The ActiGraph's GT3X-BT has been used by many researchers around the world because of its reliable 3-axis accelerometer and the Actilife software tested to interpret the signal to measure activity levels and sleep quality. Thousands of published articles can be found using this activity monitor on various topics (<https://actigraphcorp.com/research-database-access/>)

Data analysis

Descriptive statistics done using sociodemographic and questionnaires data. A qualitative approach was used to analyze interview content (Baker et al, 1992). Explanations for themes were generated and sub-themes were labelled using terms from the grey literature on NSD. A first draft of the codes was done during the summer of 2020, by the principal investigator, MR and one student in occupational therapy. A first interview was individually coded and then compared. Sub-themes were specified. When the same

exercise was repeated with another interview, the inter-rater agreement was higher than the first pre-test. Two sub-themes were also redefined. The final list of codes was numbered (see Table 1). Recordings were transcribed first by someone and then verified by the research coordinator. Then, the person who transcribed the interview identified in the text quotes that can be categorised according to the four interview themes and sub-themes. Each time the categorization was verified by the research coordinator to insure continuity. NVivo was used as the qualitative analysis software (QSR International, version 1.5.1 (940)) to facilitate categorisation and management of interview content. To confirm **H1 and H2**, those specific themes were computed and compared between cases 1, 2 and 3 regarding their frequency and intensity.

Table 1. Coding themes

1	Role and usage of the dog
1.1	Engagement and meaning of life
1.1.1	Obligations, responsibilities or valued occupation towards the dog
1.1.2	Companionship and solicitude
1.2	Socialization
1.2.1	See people
1.2.2	Develop significant relationship with others
1.2.3	Helping each other
1.3	Physical activity with the dog
1.3.1	Play with the dog
1.3.2	Walk with the dog
1.4	Help with sense of orientation
1.4.1	Great confidence in the dog
1.4.2	Keep the person safe and take the person to destination
1.5	Sleep or wake up
1.5.1	Time it takes to fall asleep or time spent sleeping at night
1.5.2	Number and duration of awakenings during the night
1.5.3	Alarm clock
1.6	Other unexpected usages
2	Obstacles and disadvantages
2.1	Negative behavior or reaction of employees or different shop or service
2.1.1	Fear of the dog
2.1.2	Allergies to dog
2.1.3	Ban on dogs in shops
2.1.4	Bad people's reaction to dogs
2.10	Fears and disinterests surrounding having a dog
2.2	Maintenance of the house or dog
2.2.1	Hair in the house because of the dog
2.2.2	Cleaning the house (dirt due to the presence of the dog)
2.2.3	Maintenance or daily care of the dog
2.2.4	Annual visit (or more) to the veterinarian
2.2.5	Food, toys, etc., costs
2.2.6	Dog grooming
2.3	Health problem or bad behavior of the dog

- 2.3.1 Too active for the person or hyperactive
 - 2.3.2 Fearful dog (thunderstorm, door slamming, etc.)
 - 2.3.3 Destructive dog
 - 2.4 Negative socialization
 - 2.4.1 Bad people's reaction in the street
 - 2.5 Unavailability of dog toileting sites
 - 2.5.1 Dog's needs for break time (for meal or sleeping)
 - 2.6 Cost and time related to dog acquisition and training
 - 2.6.1 Obedience training for pet dogs
 - 2.6.2 Training in a service dog school or elsewhere
 - 2.7 Extra care and cost required for the dog (surgery, medication, medical monitoring)
 - 2.8 Dealing with the absence, death of the dog or the possible placement of the beloved in residential care
 - 2.9 Inappropriate focus on the dog
 - 3 Advantages
 - 3.1 Reminders
 - 3.2 Well-being and quality of life (for you and your loved one's)
 - 3.2.1 Have life signification
 - 3.2.2 Happiness and other positive feelings
 - 3.3 General feeling of security
 - 3.3.1 Decreased anxiety or reduced stress
 - 3.3.2 Developing friendship with the dog
 - 3.4 Dog monitors loved one's sleep and napping
 - 3.4.1 Dog go to bed with the loved one
 - 3.4.2 Dog allows better sleep to the loved one
 - 3.4.3 Dog allows better sleep to the caregiver
 - 3.5 Independence
 - 3.5.1 Give the caregiver the opportunity to relax or some headspace to think to something else
 - 3.5.2 Less anxiety for the caregiver
 - 3.5.3 Allows the caregiver to leave home for few hours
 - 3.6 Positive economic impacts (career, keep employment, etc.)
 - 3.6.1 Allows the caregiver to keep a job
 - 3.6.2 Allows the caregiver to have a career
 - 3.7 Positive focus on the dog
 - 3.8 Other
 - 4 Future
 - 4.1 Recommendations to dog school
 - 4.2 Recommendations to caregivers
 - 4.2.1 Have a companion dog
 - 4.2.2 Not to have a companion dog
 - 4.2.3 Have a service dog
 - 4.2.4 Not to have a service dog
 - 4.3 Recommendations to health care professionals
 - 4.4 Recommendations to organizations (public health system, Alzheimer society, cities, etc.)
 - 4.5 Other
-

Economic analysis

To confirm **H3**, we compute four cost measures, all in Canadian dollars.

The first measure (med cost caregiver) is the medical costs of the caregiver in the last 30 days. It includes the costs of hospital stays in the last 30 days, as well as the costs related to visits to general practitioners, geriatricians, neurologists, psychiatrists, physiotherapists, occupational therapists, social workers, psychologists and others.

The second measure (med cost patient) is the medical costs for the person with dementia. It includes the same components as the previous measure and, in addition, the costs related to the receiving help from a district nurse, from a healthcare assistant, or using day care.

The third measure (cost helping) captures the value of the help provided by the caregiver on activities of daily living, instrumental activities of daily living and on supervision.

The fourth measure (cost of lost work) is the amount of lost revenue because of the time the caregiver had to leave its work to care for the person with dementia.

Assumptions to compute costs

All costs are computed based on the prices in place in the province of Quebec. For hospital stays, we use a value of 1,305.94 CAD per day which is the average price of a hospital day in the different health units of Quebec. (Gouvernement du Québec^a)

A visit to a general practitioner is priced at 42.85 CAD (RAMQ^a). Visits to geriatricians, neurologists, and psychiatrists are respectively priced at 51.2 CAD, 101.60 CAD and 215.00 CAD (RAMQ^b). Visits to physiotherapists and occupational therapists are priced at 47.00 CAD and 46.00 CAD respectively based on applicable rates set by CNESST (CNESST, 09-16-2022). Visits to social workers and psychologists are priced based on the hourly wage for these professions reported by the government of Quebec (respectively 33.13 CAD and 48.00 CAD) (Gouvernement du Québec^{b and c}).

Based on Hollander et al. (2009), we price an hour of help with ADLs at 21.63 CAD, and an hour of help with IADLs or supervising at 15.00 CAD. We also value receiving help from a district nurse, from a healthcare assistant, or using day care at 21.63 CAD.

Activity monitor analyses

GT3X-BT data were analysed using the Actilife software (v6.13.4). First, there was a wear time validation using the Troiano (2007) algorithm and the log sheet completed by participants. Second, the cut points used to distinguish between physical activity levels were those of Freedson (1998) designed for adults. Finally, sleep was analysed by the Cole-Kripke algorithm and manually supervised to ensure data quality. Non-parametric analyses (Kruskall-Wallis and Mann-Whitney) were used to compare group data.

Results

Sociodemographic

We conducted 56 interviews with caregivers and people with dementia who lived together. Five had a NSD (mean age of 54.8 years), 28 had a companion dog (mean age of 63.6 years) and 23 did not have a dog (mean age of 63.8 years). Among the 56 caregivers, 39 are women, 46 are spouses, and 17 are still working. The proportion of men and women is different between groups ($p=0,042$). Table 2a presents results for caregivers and statistics for the three groups. About the capabilities of participants with dementia, there is a tendency that those from the no dog group were more confined to their chair or bed: 73% *Passes more than half of the day in bed for in a chair* ($p=0,090$) and 27% *Is practically completely confined to bed or chair* ($p=0,088$). Results on the Caregiver's burden scale indicated there was a difference between the three groups only for the item 4 (Do you ever feel unable to go on?) and the item 8 (Do you ever feel that you are no longer capable of caring for the ill person?) were caregivers of the NSD group feel a lower burden than participants of the other groups. The sum of the items indicates the severity of the burden as one approaches the maximum of 64. There was a tendency ($p=0.056$) for the NSD group to have a lower burden than the other two groups (NSD: 30.0/64, companion dog: 38.8/64 (post hoc $p=0.026$) and no dog: 40.6/64(post hoc $p=0.023$)).

Table 2a. Sociodemographic information of caregivers who have done the interviews (n=56)

	Neuro service dog n=5		Companion dog n=28		No dog n=23		Kruskal Wallis test ¹
	n	%	n	%	n	%	<i>p-value</i>
Caregiver							
Men	3	60	5	16	9	39	0.042
Women	2	40	23	84	14	61	0.042
Relation with the person with dementia							
Spouse	4	80	22	79	20	87	0.739
Dating	1	20	0	0	1	4	
Children	0	0	5	18	2	9	
Brother or sister	0	0	1	3	0	0	
What is your main occupation?	3	60	8	29	9	39	0.090
Work	0	0	10	36	7	30	
Caregiver	2	40	5	18	7	30	
Retired	0	0	1	4	0	0	
Volunteerism	0	0	2	7	0	0	
Medical leave	0	0	0	0	0	0	
Mean age in years (SD)	54.8 (11.6)		63.6 (8.5)		63.8 (9.9)		0.236
Perception of capabilities mean of % (SD in %)							
-Can run errands without assistance mean	60 (55)		46 (51)		55 (51)		0.780
-Can manage daily activities without help	100 (0)		71 (46)		73 (46)		0.396
-Requires assistance to move around inside at home	0 (0)		18 (39)		27 (46)		0.364
-Passes more than half of the day in bed for in a chair	20 (45)		57 (50)		73 (46)		0.090
-Is practically completely confined to bed or chair	0 (0)		7 (26)		27 (46)		0.088
Caregiver's burden scale							
mean (SD) 16 items, score /64	23.2 ^{a,b} (4.7)		32.8 (10.2)		34.4 (11.7)		0.061
-Item 4: Do you ever feel unable to go on? 1- never to 4-very often	1.0 (0.0) ^{c,d}		1.9 (0.9)		2.1(1)		0.031
-Item 8: Do you ever feel that you are no longer capable of caring for the ill person? 1- never to 4: very often, in mean (SD)	1.0 (0.0) ^e		1.4 (0.7) ^f		1.9(0.9)		0.018

¹ Statistical difference between groups if $p \leq 0.05$

Post hoc (Mann Whitney): ^a NSD different from Companion dog ($p=0.026$); ^b NSD different from No dog ($p=0.023$);

^c NSD different from Companion dog ($p=0.045$); ^d NSD different from No dog ($p=0.010$);

^e NSD different from No dog ($p=0.040$); ^f Companion dog is different from No dog ($p=0.033$)

Table 2b shows that among the 56 people with dementia, 31 are women, 27 have a mild dementia and the most frequent causes of dementia are Alzheimer (n=15) and Parkinson (n=14). Average age differed

(0.019) between the groups: 53.6 years (NSD), 72.6 years (companion dogs) or 68.7 years (no dog). However, there was no difference in the number of years they had been diagnosed with dementia. Four of the five people who have a NSD live in the USA (where the training school for dementia dogs was located) while the fifth lived in New Brunswick, Canada (she got a dog from a training school in Manitoba, Canada). The people who have a companion dog or no dog lived mostly in Quebec (33), in five other Canadian provinces (10), and in the United States (7). Participants lived in cities (20), suburbs (20), countryside (10) or on a farm (3).

Table 2b reveals that half of the dogs were of medium size. The mean age of the NSDs was 2.4 years old and 5.4 for the companion dogs which reveals a tendency for the NSD to be younger than their counterparts ($n=0.084$). The acquisition of the NSDs was more recent (1.2 years before the interview) compared to the companion dogs (4.9 years) ($p=0.013$). Table 2b presents results and statistics for the three groups. People with an NSD all have other pets at home which is more than the other two groups ($p=0.006$). Also, there was a difference in the participants' origin mainly because none of those with an NSD come from Quebec compared to the other groups ($p=0.010$).

Table 2b. Sociodemographic information of persons with dementia and of their dogs (n=56)

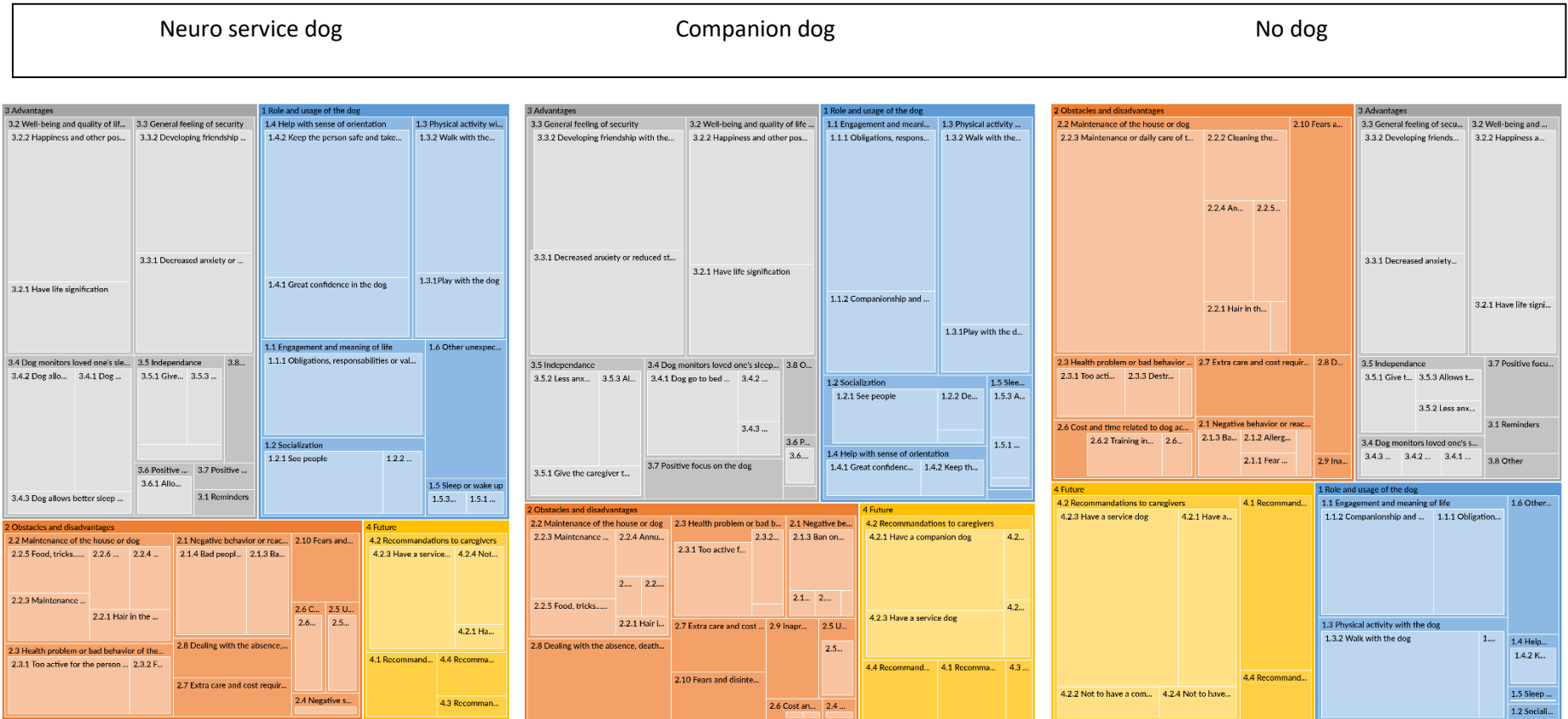
	Neuro service dog n=5		Companion dog n=28		No dog n=23		Kruskal Wallis test ¹
	n	%	n	%	n	%	p-value
Person with dementia							
Men	2	40	10	38	13	56	0.575
Women	3	60	18	62	10	44	0.575
Level of dementia							
mild	4	80	13	48	10	44	0.329
moderate	1	20	15	52	13	56	
Causes of dementia							
Alzheimer	2	40	7	25	6	26	0.080
Parkinson	1	20	2	7	11	48	
Vascular	0	0	2	7	1	4	
Aging	0	0	2	7	1	4	
Other	1	20	7	28	3	13	
Unknown	1	20	8	29	1	4	
Where do you live?							
Quebec	0	0	15	54	18	78	0.010 ¹
USA	4	80	5	18	2	9	
Saskatchewan	0	0	3	11	1	4	
Ontario	0	0	2	7	1	4	
NB	1	20	0	0	0	0	
BC	0	0	1	4	1	4	
Manitoba	0	0	1	4	0	0	
Do you live in?							
City	2	40	10	36	8	35	0.777
Suburban	1	20	10	36	9	39	
Rural	2	40	5	18	3	13	
Farm	0	0	0	0	3	13	
What is the dog size?							
Small	0	0	8	29	-	-	0.504
Medium	4	80	11	39	-	-	
Large	1	20	7	25	-	-	
Other animal in your house?							
Yes	5	100	8	32	6	26	0.006 ¹
No	0	0	17	68	17	74	
If yes, what type?							
Another dog(s)	2	40	2	20	1	17	0.799
Cat(s)	2	40	6	60	5	83	
Other	1	20	2	20	0	0	
Mean age in years (SD)	53.6 (12.0)		72.6 (11.3)		68.7 (10.4)		0.019 ¹
Number of years since diagnosed with dementia (SD)	3.2 (1.3)		3.7 (2.4)		5.6 (5.9)		0.838
Mean age of the dog (SD)	2.4 (0.9)		5.4 (3.7)		-		0.084
Number of years since the acquisition of the dog (SD)	1.2 (1.1)		4.9 (3.8)		-		0.013 ¹

¹ Statistical difference between groups if $p \leq 0.05$

Overview of the coding

With a mapping in color coming from NVivo, it is easier to appreciate differences in themes proportion between groups. Looking at the figure 1, it is possible to see that for the Neuro service dog the category “roles and usages” (in blue) takes more space than the other groups. It means that participants had more to say about it. Similarly, the category "advantages" (in grey) has a bigger proportion for the companion dogs group. Finally, for those without a dog, the category “obstacles and disadvantages” took a larger proportion during the conversation. The proportion of each subthemes is expressed in details in Tables 3-5 and will here be discussed.

Figure 1. Proportion of categories, themes and subthemes for each group



1- Usefulness of neuro service dogs and companion dogs results

Roles and usages of the dog

Table 3 shows the six roles and usages of the dog with the percentage of quotes for each case. Also, it points out the four specific themes where the exploratory research hypothesis are confirmed. When comparing the cases with percentage of quotes in the category of roles and usages, Socialization and Help with a sense of direction were the most addressed roles for dyads with the NSD. For dyads with companion dog and without dog, Engagement-and-meaning of life as well as Physical activity with the dog were the most discussed roles. People without dogs mentioned that they would like to walk with a dog as it would give them more exercise. The Sleep or wake up role was the least discussed role across three cases. Other unexpected usages were reported by dyads with NSD and without dog, but are miscellaneous: It is either a matter of the NSD making sure that the person with dementia turns off the stove after cooking, the NSD helping the person with dementia balance on stairs and during walks outside, or approaching the person with dementia in case of loss of balance; and finally, the NSD bringing or pointing out warm clothes when it is cold.

(Role of) Help with sense of direction

Neuro service dogs are taught to assist with a sense of direction, which is defined by *“an ability to know roughly where you are, or which way to go, even when you are in an unfamiliar place”* (Educalingo, 2022). Because the NSD knows where it lives, has learned certain routines for walks, and sometimes certain specific routes in public places, it can compensate for the loss of a sense of orientation in people with early dementia. This benefit is reported more frequently by dyads with NSD (NSD 26%; companion dog 11%; no dog 5%). In table 3, we can see that the sub-theme *“Keep the person safe and take the person to destination”* is more supported for dyads with a NSD than the subtheme *“Great confidence in the dog”*. Those quotes support this idea.

“They were training her, when we say home and she would know where our house was. So this one we are working on it. There is always a work in progress.” (NSD, 19-02-2019, caregiver).

“Like if she got confused or lost in a store, he will hunt for one of us to take us to the other person.” (NSD, 10-04-2019, caregiver)

“Well, it's sure that if it's adapted for him, he could even go walking alone with the dog. Because if he freezes, the dog would stop too. ... So, if he had a dog, he could make a little gesture on the harness and the dog would accompany him. It would be an easy command, ... just by making a

gesture, well the dog would go ahead and if he wants to stop it's the same thing, he makes a gesture and the dog would stop. So that would be a big advantage.” (No dog, 21-06-2021, caregiver)

Engagement and meaning of life (role in)

Healthy dogs do not need to be trained to foster Engagement-and-meaning of life, this is one of dog instinctive quality. The fact that the dog needs to be cared for allows the person with dementia to continue to feel engaged in the role of dog owner. For some, it is one of the last roles that give meaning to their life at home despite losing their cognitive faculties over the course of dementia. This role is strongly supported in the cases especially in dyads with companion dogs and no dog (NSD 21%, companion dog 38%, no dog 43%). In table 3, we can see that caregivers with companion dogs express more concerns with the sub-theme “Obligations, responsibilities or valued occupation towards the dog”, and that dyads with no dog have talked more about “companionship and solicitude”. Followings are supporting quotes for those two subthemes:

“I would say that when I'm not around he is very good at taking care of it [dog]. He is able to recognize his needs. Anyway, the dog will tell him, when he hasn't eaten, ... makes him understand that he hasn't eaten. The dog, the communication, because it's a non-verbal communication that has been established over time and I would say that it's beautiful to see, myself I'm amazed at that.” (Companion dog, 26-09-2020, caregiver)

“Oh yeah! She talks to them [dogs], she shows them things, she'll go somewhere from one place to another and then “come and see!” You know, like, come with me and, oh yes, she makes sure they're always around her.” (Companion dog, 05-09-2020, caregiver)

“It would give him company, he could go for a walk with the dog. He would have a small living being to take care of. I think that would stimulate him.” (No dog, 19-04-2021, caregiver)

“I'd literally be lost somewhere without mine [NSD]. God, I don't know where I would be. And today, Sky basically dragged me to kickboxing and dragged me home. It's because she knows the routine and that's what we do. So, Tuesday was a wired day. She knows when I'm off. And she just got to keep the routine going? And, that's so important ... I mean, routine is everything [...] because their dog is going to keep in there, that's a definitely great thing.” (NSD, 30-10-2020, person with dementia)

“So, she's there, hum... so she's my protection, she's my companion, she makes me be more responsible with things, like I have a job to do with her, which keeps my mind going somewhat.” (NSD, 07-05-2019 person with dementia)

“I would recommend one, yes. Just for the purpose. It gives you purpose; gets you up, keeps you motivated or active. And he’s a good companion, gives you emotional support and yeah I would recommend it to anybody if they had a chance to get one.” (NSD, 06-09-2019, person with dementia)

“Okay, it’s more of a presence, you know? He’s there, I mean, when we get up in the morning, if she’s not in the best of moods, which happens sometimes, the dog comes and he goes beside the bed or something, and sometimes he barks and, as soon as she notices him, that changes her attitude. You know? Like, right away. Oh, look! There’s our dog! You know? So, we noticed that. I, sometimes, will even call the dog, when we need to have a change of attitude.” (Companion dog 10-09-2019, caregiver)

“I mean, if my wife is not feeling well, she [dog] curls up and watches her. Or a couple weeks ago, she wasn’t well, and our dog - she went up to bed and stayed with her.” (Companion dog 17-05-2019, caregiver)

Doing physical activity with the dog

Neuro service dogs are taught to promote physical activity in their owner. According to the World Health Organisation (2021), “Physical activity refers to all movement including during leisure time, for transport to get to and from places, or as part of a person’s work. Both moderate- and vigorous-intensity physical activity improve health. Popular ways to be active include walking, cycling, wheeling, sports, active recreation and play, and can be done at any level of skill and for enjoyment by everybody”. Walking the dog outside and taking care of it in the house increases the owner’s physical activity. This role was highly discussed in dyads with companion dogs and no dog (NSD 16%, companion dog 31%, no dog 37%). The sub-theme “Play with the dog” is supported in an equivalent way in all cases (table 3). The “Walk with the dog” sub-theme is two times less discussed in the NSD group than in both other groups (table 3). However, the quotes confirm that there is much more moderate- and vigorous-intensity physical activity reported by owners of NSD than walk the dog or play with the dog (light or sedentary physical activity).

“I do the routine with the kickboxing and the dog walking. I do that Monday to Thursday. I usually take our own dogs out and do a bunch of stuff on Fridays just walking and running at the park and go to the beach or whatever. And then, you and I usually take them on the weekend to do things. So, I’m very active. [...] I wear a Fitbit, all the time. I have reach 20 000 steps a day.” (NSD, 2020-09-30, person with early dementia)

“Well, when we’re in the city, he generally just goes in the backyard, we have a big backyard. So I... once in a while, we’ll walk along the river.” (Companion dog, 2019-05-18, caregiver)

“...we’re up and about moving around and playing with them and letting them out and walking around with them and stuff.” (Companion dog, 2020-01-27, caregiver)

"I) Okay, are you fairly physically active? D) Ah I try to be yeah. My Parkinson limits sometimes but... I) Okay, so do you think that the dog might help you with maintaining your physical activity? I) That is the main reason that we are getting it." (No dog, 10-03-2019, person with dementia)

(Role in) Sleep or wake up

Neuro service dogs are taught to assist with quality of sleep and waking up. It is recognized that 60-70% of people in the early stages of dementia present with disturbances of sleep and wakefulness (Wennberg et al, 2017), and that the reassuring presence of a dog could help them. By its presence, the dog helps to fall asleep or to go back to sleep, or even sometimes wake up its master for certain considerations. However, only one caregiver in the NSD group addressed this point, while nine caregivers did so for companion dogs. Very few caregivers or persons with dementia addressed the subthemes "Time it takes to fall asleep or time spent sleeping at night", "Number and duration of awakenings during the night" and "Alarm clock".

"So, intervening during a nightmare,... C: Yes, oh yes, it's because he needs to get out of his nightmare and that's what I do. When he has nightmares, I get up and go calm him down." (No dog, 07-06-2021, caregiver)

"When my husband has a nap, she (dog) is always right there and they are comforting each other. [...]. Before my husband even gets up in the morning, she jumps up on the bed and she lick his face and wakes him up." (NSD, 19-02-2019, caregiver)

"Oh yes! I definitely get a better sleep when the dog is lying beside me. It's like a safer feeling." (NSD, 30-09-2020, person with dementia)

"Yeah, he'd [dog] wait until I fell asleep and he'd go and cry on her side and she'd pick him up and put him on the bed. But, he'd know not to wake me up, but in the morning he'd be there, waiting for her to get up." (Companion dog, 19-06-2019, caregiver)

Table 3. Five roles and usages of having a dog, documented by caregivers living with a person with dementia, with a neuro service dog, companion dog or no dog (n=56).

Themes Subthemes	Dyads with neuro service dog			Dyads with companion dog			Dyads without a dog		
	n	q.	% q./c.	n	q.	% q./c.	n	q.	% q./c.
Category of roles and usages	5	81	100	28	197	100	20	65	100
Engagement-and-meaning of life	5	17	21	27	74	38	15	28	43
Obligations, responsibilities, or valued occupation towards the dog	5	10	12	24	50	25	10	11	17
Companionship and solicitude	4	7	9	14	24	12	10	17	26
Socialization	5	21	26	17	25	13	1	1	2
See people	5	19	23	14	19	10	1	1	2
Develop significant relationship with others	2	2	2	5	6	3	0	0	0
Physical activity with the dog	5	13	16	26	62	31	16	24	37
Play with the dog	2	4	5	9	11	6	4	4	6
Walk with the dog	5	9	11	24	51	26	15	20	31
Help with sense of direction	4	21	26	14	22	11	3	3	5
Great confidence in the dog	3	6	7	9	12	6	0	0	0
Keep the person safe and take the person to destination	4	15	19	8	10	5	3	3	5
Sleep or wake up	1	2	2	9	12	6	1	1	2
Time it takes to fall asleep, or time spent sleeping at night	1	1	1	5	5	3	0	0	0
Number and duration of awakenings during the night	0	0	0	1	1	1	1	1	2
Alarm clock	1	1	1	5	6	3	0	0	0
Other unexpected usages	3	7	9	2	2	1	5	8	12

q. = quotes

% q./c. = percentage of quotes of this category

Advantages of having a dog

Table 4 shows seven benefits or advantages of having a dog. Also, it points out three specific themes where the exploratory research hypothesis H1 is confirmed. **General feeling of security** is the theme mentioned by most participants in all cases (NSD 29%, companion dog 34%, no dog 36%) but only by 14 of the 23 participants in dyads with no dog. The related sub-themes are "Decreased anxiety or reduced stress" and "Developing friendship with the dog" (see table 4). **Well-being and quality of life** is also widely supported in all three cases (NSD 31%, companion dog 28%, no dog 30%) but only reported by 9 of the 23 participants in dyads with no dog. Similarly, the related sub-themes, "Have life meaning" and "Happiness and other positive feelings" are supported in a similar way regardless of the group (table 4).

Dog monitors loved one's sleep and napping is the third most cited advantage by participants with a dog (NSD 21%, companion dog 13%, no dog 8%) but again only reported by 4 of the 23 participants in dyads with no dog (table 3). Subthemes "Dog goes to bed with the loved one", "Dog allows better sleep to the loved one" or "Dog allows better sleep to the caregiver" supported this advantage (table 4).

Independence is a theme that refers to the idea that having a dog in the home gives the caregiver more freedom to pursue other roles because the dog can take care of their loved one in their absence. In other words, the dog gives the caregiver independence. This is reported by 5/5 of the family caregivers of the NSD group, 20/28 of the companion dog group and 6/23 for the no dog group (27%). Related sub-themes are "Give the caregiver the opportunity to relax or some headspace to think about something else", "Less anxiety for the caregivers" and "Allows the caregiver to leave home for a few hours" (table 4). **Positive economic impact** of having a service dog at home is an advantage since it "Allows the caregiver to keep a job", as cited by 6 caregivers in total (NSD 3%, companion dog 2%, no dog 0%). No group members supported the sub-theme, "Allows the caregiver to have a career". Quotes from caregivers who have NSD in the home confirm H1 for these two themes, i.e., the presence of a NSD has more positive impact on the caregiver's independence and on personal finances than the presence of a companion dog. Here are quotes supporting the first sub-theme.

"I'm about to take over a part time position there at the church. So, having the dog does enable me to go to work." (NSD, 25-02-2019, caregiver).

"I: Is there an economic impact? C: Oh yes. Oh yes. Basically, when she gets home, I check on the camera [from my desk at work] if she's in the room and the dogs are with her and I have no fear of her getting lost. So, that's a big bonus. Because I know she's active. And I can track her on my phone with two apps. So, when she does get somewhere she's not supposed to, Sky does surveillance at home. I know where she is." (Companion dog, 6-10-2020, caregiver)

Positive focus on the dog by the person with dementia is an advantage when, for example, taking care of the dog to keep him healthy rather than worrying about other things that might cause anxiety. This theme was seen as an advantage (NSD 2%, companion dog group 5%, no dog 6%) mostly supported by 11 participants in dyads with companion dogs (table 4). **Reminders** coming from the dog are seen as an advantage of having a NSD (NSD 2%, companion dog 0%, no dog 4%), but only reported by one participant with a NSD, one with a companion dog and 3 participants without dog. H1 is confirmed here, that presence of a NSD has more positive impact on the activation of the memory of the person with dementia (for doing things, routine) than the presence of a companion dog.

Table 4. Seven advantages of having a dog, documented by caregivers living with a person with dementia, with a neuro service dog, companion dog or no dog (n=56).

Themes Subthemes	Dyads with neuro service dog			Dyads with companion dog			Dyads without a dog		
	n	q.	% q./c.	n	q.	% q./c.	n	q.	% q./c.
Category of advantages	5	62	100	28	261	100	22	80	100
General feeling of security	5	18	29	26	89	34	14	29	36
Decreased anxiety or reduced stress	4	8	13	21	42	16	9	13	16
Developing friendship with the dog	5	10	16	21	47	18	11	16	20
Well-being and quality of life	4	19	31	23	74	28	9	24	30
Have life signification	3	6	10	18	30	11	5	6	8
Happiness and other positive feelings	4	13	21	21	44	17	9	18	23
Monitoring loved one's sleep and napping	3	13	21	17	33	13	4	6	8
Dog goes to bed with the loved one	3	5	8	14	23	9	2	2	3
Dog allows better sleep to the loved one	3	6	10	6	6	2	2	2	3
Dog allows better sleep to the caregiver	1	2	3	3	4	2	2	2	3
Independence^{H1}	5	6	10	20	40	15	6	11	14
Opportunity to relax or some headspace to think to something else	3	3	5	7	9	3	4	5	6
Less anxiety for the caregiver	1	1	2	12	19	7	3	3	4
Allows the caregiver to leave home for few hours	2	2	3	12	12	5	3	3	4
Positive economic impacts^{H1}	1	2	3	5	5	2	0	0	0
Allows the caregiver to keep a job	1	2	3	5	5	2	0	0	0
Allows the caregiver to have a career	0	0	0	0	0	0	0	0	0
Positive focus on the dog	1	1	2	11	13	5	4	5	6
Reminders coming from the dog^{H1}	1	1	2	1	1	0	3	3	4

q. = number of quotes

% q./c. = percentage of quotes of this category

H1 = the first exploratory research hypothesis is confirmed: the presence of a NSD has more positive impact - on this theme- than the presence of a companion dog.

Disadvantages, inconveniences, and obstacles of having a dog

Table 5 shows the 10 inconveniences reported in the three cases and one confirmation of the second exploratory research hypothesis for one subtheme. The highest percentage of quotes in the category of disadvantages goes for the dyads who do not have a dog, for the **Maintenance** supported with 6 sub-themes shown in table 5 (NSD 29%; Companion dog 27 %; no dog 53%). The theme **Fears and disinterests surrounding having a dog** is also an important inconvenient for dyads with no dog (NSD 7%; Companion dog 7 %; no dog 14%). Here are some quotes that support this.

“The only issue I had was, being that he was not a service dog or trained to be a service dog, I was scared that he would trip the wife. Being that she had dementia, she’d forget that he’s around and he’d get in between her legs or something, and trip her.” (Companion dog, 30-09-2019, caregiver)

“Well, the disadvantage is when you have mobility issues like I have now, that you can easily trip over them ... If they're not trained just to stay out the way like a service dog will perhaps be. They're not trained to stay out of the way, so they don't [...] the cats and the dog will do that sometimes, they will try to run real fast in front of me when I'm going back to the bedroom and cut me off. I mean they can just cut you right off and yeah because they're that fast. Yeah and so I had to watch that because they'll do that like late at night when you're not watching and so that can be a danger. I have problems with stairs. So that's an issue.” (Companion dog, 30-04-2020, caregiver).

Dog’s health problem or bad behavior is an inconvenient and it is supported by 3 sub-themes in table 5 (NSD 19%; companion dog 17 %; no dog 9%). This theme more discussed in dyads who have a dog. Here are quote related to this theme:

“Most trained service dogs, well they have times when they are ill like a bladder infection or something. You just never know. Most service dogs can hold on for a long time.” (NSD, 19-02-2019).

“C: At the gym. Uh that’s another incident that happened, [...] it’s a very tense situation, because M. was exercising on a machine, and this other lady walked around to access a machine nearby, and that startled Teagan. And so she barked. And then M. got anxiety and said, “I think I better take her home”. And the person that’s there said it was probably a good idea. But we... I think the person that was there, the staff person, was thinking more of M. being anxious about it... than to the dog barking. Nobody had... as I heard M., it seemed like nobody had a negative response to the dog barking, except M”. M : “Yes... This was the first time, I mean I’ve been going down there for 3 months now, and this was the first time she barked and they said this was so unusual.” (NSD, 25-01-2019, caregiver and person with dementia).

Inappropriate focus on the dog is a disadvantage when the person with dementia lacks discipline or authority for the dog's well-being. This happens when it is a pet dog (NSD 0%; companion dogs 6%; no dog 1%).

“If I can tell you quickly, a small part of the daily life is that my mother, because she has dementia, she forgets things and she feeds the dogs. Every time, I tell her that she should not feed the dogs, because there are things that are toxic for the dogs. What happens is that I discipline the dogs, ... because they bark for nothing or ... they jump. I discipline them and when I baffle them, they go to her.” (Companion dog, 24 -09-2019, caregiver translated).

Common to all three cases, the theme of **Dealing with the absence of the dog** is often mentioned as a disadvantage, concerning death of the dog or placement in residential care. Some people do not want to have a dog because of the grief that comes when it passes away (NSD 7%, companion dogs 18%, no dog 4%).

“We were never able to get another. As soon as you see a dog, you immediately think of the other and it was such a good dog and it's hard to see if you could have one that would be like him there.” (No dog, 15-11-2021, caregiver)

“ I know that, let's say I'm in a support group and there's someone in there, that her spouse has been in residence for many years. Her son has a dog. ... when he goes to see his dad, he brings the dog. ... it's allowed. So, if I ever had the dog with me probably I would bring it when I go to see my spouse if they allow it.” (Companion dog, 26-09-2020, caregiver translated)

“The placement, I have thought of that and I have wondered how that would work, and it scares me to think of it, and so I find since we don't know hundred percent how the future is going to fold out. I'm trying my best to cope by that mindfulness and live one day at the time. When I start to think about what will become of Yukon and R., if and when that time comes, I am so attached to her but I don't know.” (NSD, 19-02-2019).

The theme **Dog's need for break time** (for meal, sleeping, toileting site) was mentioned as an inconvenience by 8 participants (NSD 1%, companion dog 2%, no dog: 0%). The need to access canine toileting facilities during travel was particularly challenging.

*“Our dog is... she had the mistake (of defecating) three times so far in public, we did everything we could to make sure that she was relieved, but you know at an **airport**, uh she (the dog) went in the comfort room, and she just had a big old pile right in the middle of a walkway. There, we circled it with our luggage and ourselves, I ran off and M. (the person with dementia) picked it up, and then I came out with towels and soap and cleaned it up. Unfortunately, it's going to happen*

once to them all...[...]. The airport, they had the facilities, but she (the dog) wouldn't use them. [...]. The lady who had supervision of the facility actually dropped in while we were there, and she said many dogs who are very responsible, just will not go in those kinds of artificial environments". (NSD 25-01-2019, caregiver).

The **Dog acquisition and training** (time, cost) appears to be an inconvenient but not a matter in dyads with a companion dog (NSD 5%, companion dogs 1%, no dog 6%). One dog school may charge an expensive price (no waiting list) and another school may absorb the cost with donations (long waiting list).

"So I kept searching and I found the company, I found a couple. One in Vancouver and then this one in Winnipeg and we went with them. Now to have a dog trained through a company. It is pricey. We paid 25,000 CAN\$ dollars, which is a lot." (NSD, 19-02-2019, caregiver)

"Well our daughter... well it took a year and a half to two years before the dog was trained" (NSD, 10-04-2019, caregiver)

"The total cost, I think, was around 15,000 to 16,000 US \$ dollars, with transportation, room and board, and those kinds of things. The dog itself was 14, 500 US \$ dollars under contract, and that's about... that's a little over half of what the actual costs are." NSD, 25-01-2019, caregiver?

The **Extra care and cost required for the dog** is discussed in the same proportions in the three cases (NSD 7%, companion dogs 8%, no dog: 7%). It was about surgery, medication, medical monitoring.

Table 5. Ten inconveniences, disadvantages, and obstacles of having a dog, documented by caregivers living with a person with dementia, with a neuro service dog, a companion dog, or no dog (n=56)

Themes Subthemes	Dyads with neuro service dog			Dyads with companion dog			Dyads without a dog		
	n	q.	% q./c.	n	q.	% q./c.	n	q.	% q./c.
Category of inconveniences	5	42	100	27	156	100	22	116	100
Reaction of employees or clients	5	8	19	12	17	11	6	8	7
Fear of the dog	0	0	0	1	1	1	2	2	2
Allergies to dog	0	0	0	2	2	1	2	2	2
Ban on dogs in shops	3	3	7	7	12	8	3	3	3
Bad people's reaction to dogs	3	5	12	2	2	1	1	1	1
Maintenance	4	12	29	17	42	27	17	61	53
Hair in the house because of the dog	1	2	5	2	3	2	4	4	3
Cleaning the house	0	0	0	3	3	2	6	7	6
Maintenance or daily care of the dog	1	3	7	13	17	11	14	39	34
Annual visit to the veterinarian	2	2	5	6	7	4	5	6	5
Food, tricks	2	3	7	8	9	6	4	4	3
Dog grooming	2	2	5	2	3	2	1	1	1
Dog's health problem or bad behavior	2	8	19	17	26	17	7	10	9
Too active for the person or hyperactive	2	6	14	14	18	12	4	5	4
Fearful dog (thunderstorm, door slamming)	2	2	5	6	7	4	1	1	1
Destructive dog	0	0	0	1	1	1	4	4	3
People's reaction in the street	1	1	2	2	2	1	0	0	0
Dog's needs for break time (meal, sleeping, toileting sites)	2	2	5	6	6	4	0	0	0
Acquisition and training (time, cost)	2	2	5	3	2	1	6	7	6
Obedience training for pet dogs	0	0	0	1	1	1	2	2	2
Training in a service dog school or not	2	2	5	1	1	1	3	5	4
Extra care and cost (surgery, medication, medical monitoring)	2	3	7	9	12	8	6	8	7
Dealing with the absence of the dog (death of the dog, placement in residential care)	3	3	7	17	28	18	4	5	4
Inappropriate focus on the dog	0	0	0	6	10	6	1	1	1
Fears and disinterests of having a dog	3	3	7	7	11	7	11	16	14

q. = quotes

% q./c. = percentage of quotes of this category

2- Socialization role as a result

Neuro service dogs are trained to contribute to socialization. Staying socially connected is the principal recommendation from the Alzheimer Society of Canada (2022). From the first onset of symptoms of dementia, socialization is encouraged so as “to make the most of your daily opportunities to socialize, to practice a random act of kindness, find time to volunteer, to combine social interaction with an activity and to maintain old friendships and make new ones”. Walking alone with a dog may encourage people to approach them and talk to them about their dog, thus keeping them connected to society. However, if the dog is not a NSD (i.e., not wearing a vest that certifies it is a dog trained to support the person and allowed to public facilities), it may be difficult to enter businesses, especially churches, clinics and restaurants with a dog. We had expected socialization to be more intense with an NSD because it is allowed to accompany its owner inside public or commercial buildings. We also observed that the sub-theme "See people" is more discussed in dyads with a NSD than the other dyads (NSD 23%; companion dog 10%; no dog 2%) (Table 3). Furthermore, “Developing significant relationships with others” seems possible when having a dog with you (NSD 2%, companion dog 3%, no dog 0%). This is illustrated in the following quotes.

“Oh! My life is definitely better with the dog. I’m not usually a social butterfly by any means. I hope to talk to a lot of people, but when I’m out with the dog I have a lot of people to talk to me. I get to meet the neighbors ... I got a lot of friends in this neighborhood because of the dogs. You get to meet a lot more people in general.” (NSD, 30-09-2020, person with dementia)

“So the ability to connect words in a conversation is difficult for him. When he talks about the dog, it gives him something familiar to talk about and something that he knows. [He is] not put on the spot so much and so as far as socialization goes, I would say it helped because [...]. he has a topic to talk about, that he feels confident with.” (NSD, 19-02-2019, caregiver)

“The people at church are very impressed with her [the dog], because I sing in the choir, and she has to be right there with me, so she’s in the choir when we’re performing. And one day, a lady that was [...] standing next to me, who has Alzheimer’s, was losing her balance, and Teagan had the wherewithal to turn around and nuzzle her and get her back onto the stool. [...] She’s very alert to everything around her, it’s amazing [...]. This particular church is fairly new to both of us and these folks have just adopted her, hum to the individual. Every person that is in that congregation has adopted her.” (NSD, 25-01-2019, person with dementia)

“I think so. My husband was always a very private quiet kind of man. I think the dog has brought out more of conversations with him. He is able to talk to the dog and use the dog almost as a tool for conversation... our neighbors that are here full time engages with the dog which helps my husband engage with them.” (Companion dog, 18-05-2019, caregiver)

Disadvantages reported related to an increase in socialization

Reaction of employees or clients if negative can be a real inconvenient; it is supported by 4 sub-themes (NSD 19%; companion dog 11 %; no dog 8%). Even though it rarely happens when the dog is a service dog, a clinic clerk or staff's rejection of a service dog can be profoundly inconvenient. The subtheme "Ban on dogs in shops" is definitively the obstacle encountered with companion dogs. This confirms H2 where the presence of a NSD results in the person with dementia accessing more indoor and outdoor public sites than with a companion dog. Following are quotes from owners of NSD and companion dogs referring to "Ban on dogs in shops" and "Bad people's reaction to dogs."

"When she gets the first service dog, she went to the Dollar store, and they say that she couldn't have the dog in there. [...]. I wrote an email to the company, and they ended up having a staff meeting the following day, because they were just being ridiculous". (NSD, 30-09-2020, caregiver)

"And yesterday, M. was at a doctor's appointment, and we believe the doctor just really doesn't like Teagan being in there, and when that doctor came to the room he just stuck... opened the door, stuck his head in the room and said something, and Teagan responded with a bark. And then, hum... So the doctor asked... said for her not to take Teagan there anymore. And we understand this, we know that... we think it was excessive on the doctor's part but at the same time Teagan is not [supposed] to bark in public. (NSD, 25-01-2019, caregiver).

"In USA, we don't go anywhere inside with the dogs usually. In the coffee shops, the dogs have to stay outside". (Companion dog, 28-02-2020, caregiver).

"Even going to the hardware store, they look at us with big eyes and say "go put your dog in the car". The only mall where they accept dogs is Place de la Cité. So, again, it's not a nice mall to walk around in. ... I would like to be able to take them everywhere, but it seems that they are afraid that they will do their business. I always have bags and try to be careful, but maybe some people don't pick up after themselves like I do. Maybe that's why there are a lot of stores and then shopping malls where they don't want to see it". (Companion dog, 27-01-2020, caregiver translated).

Common to all three cases, **People's reaction in the street** was encountered as an inconvenience by only 3 participants (NSD 2%, companion dog 1%, no dog 0%). However, the size or a less popular dog breed may scare people in public.

"C: Because of the size of the big ones, most of the time people back off and they kind of get nervous and scared. People that like animals will make comments, like "oh how pretty", "that's nice" or "they're good to get it", they'll make positive comments, and people that are fearful of

animals they are negative. They more often will shy away or cross the street. I: Okay. And the fact that the two of your dogs are Pitbull's, are there some people afraid of that because of the breed? C: I think that's the main reason why they get afraid of it. People have a negative tone to their breed". (Companion dog, 09-07-2020, caregiver)

3- Quality of life results and economic analyses

The two questionnaires that measured quality of life show no difference between the groups, indicating that having a dog does not increase nor decrease the aspects of quality of life that were studied.

The ICECAP-O (ICEpop CAPability) is an instrument used with elderly populations to measure well-being according to 5 aspects: attachment (love/friendship), thinking about the future, rewarding activities, pleasure and independence. Each answer of this questionnaire must have been weighted according to the ranking given by participants of a larger study who validated this questionnaire for the elderly population (Coast et al 2008). Participants to this study realized that the value of this scale should not be linear as there is a bigger gap in actual quality of life, for example, between "a lot of" and "a little of" love and friendship, than between "all of" and "a lot of" love and friendship. Table 6 shows the results of this rescaling. A higher score indicates a higher quality of life (max 1.0). There was no statistical difference between total scores. The only difference is in the question 2 where participants with no dog see, overall, the future with "some concern" where participants of the other groups see is with "little concern".

Table 6. Results of the ICECAP-O questionnaire weighted for the elderly population

ICECAP-O	Neuro service		Companion		No dog		Kruskal-Wallis <i>p</i> -value
	dog n=4		dog n=24		n=19		
	mean	SD	mean	SD	mean	SD	
total score	0.65	0.24	0.73	0.17	0.74	0.14	0.668
1. Love and Friendship	0.21	0.05	0.18	0.09	0.20	0.07	0.660
2. Thinking about the future	0.10	0.05	0.12	0.05	0.07	0.05	0.006*
3. Doing things that make you feel valued	0.11	0.07	0.14	0.05	0.15	0.04	0.263
4. Enjoyment and pleasure	0.14	0.03	0.13	0.03	0.14	0.02	0.704
5. Independence	0.07	0.14	0.15	0.07	0.18	0.04	0.479

* $p \leq 0.05$

The ASCOT (Adult Social Care Outcomes Toolkit) is a questionnaire which measures the quality of life related to social care among caregivers by measuring 7 aspects of life (feeling supported, social participation, time for oneself, etc.). There was no French version available, thus reducing the number of participants that could answer the questionnaire. A higher score indicates a higher quality of life.

The table 7 shows the results of the total score and of each items. A total score from 10 to 12 indicates that improvements are needed in some aspect of people's lives. Although there is no statistical difference, it is possible that more participants with a neurological service dog could confirm this increase in quality of life.

Table 7. Results of the ASCOT questionnaire

	Neuro service dog n=4		Companion dog n=18		No dog n=11		Kruskal- Wallis
	mean	SD	mean	SD	mean	SD	p-value
Total score	12.5	2.4	10.3	4.4	10.6	3.9	.423
1. How you spend your time	1.5	0.6	1.1	0.7	1.4	0.7	.280
2. How much control you have over your daily life	1.5	0.6	1.5	0.8	1.5	0.8	.977
3. Thinking about how well you look after yourself	1.0	0.0	1.2	1.0	1.5	1.0	.475
4. How safe you feel	3.0	0.0	2.6	0.9	2.5	0.7	.418
5. How much contact you have with people you like	1.8	0.5	1.2	0.8	0.9	0.9	.141
6. Space and time you have to be yourself in your daily life	1.5	1.0	1.2	0.9	1.5	0.8	.780
7. Feeling supported and encouraged in your caring role	2.3	1.0	1.6	0.8	1.3	0.9	.190

Resource utilization in dementia (RUD) was the main questionnaire used for the economic analyses. It measures healthcare resource utilization among older adults with dementia and their caregivers, and time spent on formal and informal care by caregivers.

The table 8 shows the medical costs and compares it between groups. The “med cost caregiver” (medical cost of the caregiver) is the medical costs of the caregiver in the last 30 days. It includes the costs of hospital stays in the last 30 days, as well as the costs related to visits to various health professionals. The “med cost patient” is the medical costs for the person with dementia. It includes the same components as the previous measure and, in addition, the costs related to the receiving help from a district nurse, from a healthcare assistant, or using day care. The “med cost total” is the sum of these two variables. The “cost helping” captures the value of the help provided by the caregiver and the “total cost without

work” is the total cost considering the medical costs and value of the help provided, leaving the impact on the caregivers’ paid work for table 9. There was no statistical difference in the medical costs between groups. The mean value of the help provided by the caregivers in each group was more similar (between 3799 and 4396\$ per month). It consisted of the main expense reported and was not significantly lower in the neuro service dog group.

Table 8. Medical costs and value of the help provided in the last month

	Neuro service dog n=5		Companion dog n=27		no dog n=22		Kruskal Wallis
	mean	SD	Mean	SD	Mean	SD	p-value
Med cost caregiver	\$55	\$78	\$68	\$98	\$2 022	\$9 025	.860
Med cost patient	\$99	\$174	\$296	\$661	\$1 752	\$6 696	.744
Med cost total	\$155	\$251	\$363	\$682	\$3 774	\$10 913	.752
Cost helping	\$3 799	\$3 715	\$4 349	\$3 944	\$4 396	\$4 371	.927
Total cost without work	\$3 954	\$3 821	\$4 713	\$4 146	\$8 171	\$13 219	.848

The table 9 captures the lost of income because of the time, in the last month, that the caregiver had to leave work to care for the person with dementia. No statistical difference could be observed. The “total cost with work” is the total of the four cost measures calculated. No difference could be seen considering especially the large variability of the medical costs.

Table 9. Cost of missing work and total cost

	Neuro service dog n=3		Companion dog n=9		no dog n=6		Kruskal Wallis
	mean	SD	Mean	SD	Mean	SD	p-value
Cost of lost work	\$1 440	\$1 270	\$724	\$903	\$413	\$974	.360
Total cost with work	\$5 151	\$4 476	\$5 009	\$4 471	\$12 792	\$22 033	.972

One more thing that should be considered in this analysis is the price of a neuro service dog. Based on the two sources of this study, the cost for the client is around 25 000 CAD. Furthermore, the cost of maintaining a service dog at home was estimated to 1549 CAD in 2016 (Vincent et al, 2016)

4- Physical activity and sleep results

With the help of their caregiver, people with dementia wore at their wrist an activity monitor for 7 days and 7 nights. The caregivers also completed a log sheet to inform us of when the person was not wearing the device (e.g. in the shower) and to confirm us the time the person was going to bed and the moment they get up.

The table 10 shows the results of the sleep analyses. The sleep efficiency consists of the percentage of the time sleeping (hours of sleep), detected by the device, and the total time passed in bed (hours in bed). The sleep efficiency was similar between groups. For the “hours of sleep” and the “hours in bed”, the statistical analysis did not find a difference between groups.

There is no difference in the number of awakenings per night on average and it cannot be concluded that the number of minutes of “wake after sleep onset” and of “time of awakening” are different due to the higher variability observed. The same results were obtained for the “sleep fragmentation index”. It represents the restlessness during the sleep and the higher the index, the more sleep is disrupted.

Table 10. Results about the sleep analyses of people with dementia

	Neuro service dogs n=4	Companion dogs n=18	No dog n=15	Kruskal- Wallis p-value
Hours in bed	6.7 (0.7)	8.3 (2.0)	8.5 (1.4)	0.133
Hours of sleep	6.6 (0.9)	7.6 (2.0)	7.6 (1.1)	0.365
Sleep efficiency (%)	93.1 (3.3)	92.4 (5.5)	90.3 (8.1)	0.921
Number awakenings	9.2 (4.6)	9.3 (5.0)	8.7 (4.3)	0.926
Wake after sleep onset (min)	23.1 (12.4)	36.9 (28.1)	47.0 (43.7)	0.707
Average awakening length (min)	2.7 (0.6)	3.7 (2.4)	4.8 (3.5)	0.499
Sleep fragmentation index (%)	19.8 (5.4)	23.2 (12.9)	20.3 (11.4)	0.855

The table 11 presents the physical activity results of people with dementia. Data are presented as the percentage of the time the person passed in activity levels. The sedentary level consists of low-level activities done, for example, when sit down (eating, watching TV, reading, etc.). No difference was detected between groups. The activity monitor was able to measure that people who do not have a dog spend a larger portion of their day doing light activities (e.g. quiet standing activities). Even though there is no difference in the moderate intensity activities (e.g. brisk walking) between groups. We can observe

a tendency for those with a neuro service dog to spend more time in moderate activities than those without dogs when we combine this result with the observations of caregivers. As shown in table 2a, caregivers tended to notice less that their loved one spent the majority of their time sitting or lying down. (both for “more than half” and “almost all”).

Table 11. Physical activity results of people with dementia

	Neuro service dogs n=4 %	Companion dogs n=18 %	No dog n=15 %	Kruskal- Wallis <i>p</i> -value
Sedentary level	63.3 (8.1)	64.2 (12.3)	58.7 (7.8)	0.379
Light level	28.2 (4.1)	29.2 (9.5)	37.1 (8.8)	0.038*
Moderate level	8.5 (4.4)	6.6 (5.2)	4.2 (2.5)	0.262
Vigorous level	0.0 (0.0)	0.0 (0.0)	0.0 (0.0)	1

* $p \leq 0.05$

Discussion

Aim 1

This is the first study that has examined the impact of canine assistance on both the person with dementia and their caregiver living in their home. Previous literature reports only animal assisted intervention in nursing homes and for persons with moderate to severe dementia (Briones et al., 2019; Kårefjärd & Nordgren 2018; Lai et al., 2019; Majić et al., 2013; Olsen et al., 2016 a; b; Olsen et al. 2019; Parra et al., 2022; Wesenberg et al., 2019). The first aim of this project was to examine the impacts of canine assistance on both the person with dementia and their caregiver. After reviewing the interviews, it appears that the roles of canine assistance and their advantages overcome their disadvantages and we can conclude that the presence of a neuro service dog or a companion dog positively impact both the person with dementia and his/her caregiver. Thus, our first hypothesis (H1) is confirmed. In that regard, our study documented five specific roles and usages of a NSD. The Socialization, and Help with a sense of direction roles are unique to NSDs, as well as Other unexpected usages. On the other hand, “Engagement and meaning of life” and Physical activity roles were more addressed in dyads with companion dogs and without dog. Participants in these groups associated a dog with physical activity in terms of walking and playing with the dog as participants with a NSD will describe physical activities facilitated with by the dog, like an access to the gym. The role of Sleep or wake up appears to be a less predominant role for both the NSD or the companion dog, compared to the other roles. Moreover, our content analysis reveals additional impacts of canine assistance in terms of 7 potential benefits and 6 considerations (figure 2). Previous literature on service dogs with other populations (motor impairments, PTSD) is different in terms of roles, usages and advantages, but similar regarding disadvantages (Lessard et al., 2018; Vincent et al., 2016).

Aim 2

The second research aim was met because we documented the informal acceptance of canine assistance in public places as well as the socialization role as a result. A companion dog cannot go in as much places than an NSD but it is also considered the friend of the person with dementia, it walks with them, and contributes to their socialization (EODAF, 2022). In the disadvantages, we can see that a NSD is sometimes not welcomed in some public places but was uncommon and can usually be resolved.

Companion dogs are not authorised in stores, but they are well accepted on the street and parks the vast majority of the time.

The NSD can guide the person with dementia in their daily activities outside the home, and brings them back safely. We also observed similarities between those two groups in the impacts certain roles, especially if the owner of the companion dog is directly the person with dementia. Both NSD and companion dogs help enhance engagement by the person with dementia in the completion of daily routines and that this gives meaning to their lives.

The NSD facilitates also the socialization of the person with dementia. Several examples have been reported of the person being approached by others in a store, a restaurant, an airport, a gym, a church and a clinic, which goes beyond the socialization during walks with the dog. Furthermore, dyads of persons with dementia and caregivers with a NSD or a companion dog are informally socially engaged more frequently than those with no dog. People who love dogs will come up and talk about the dog, and the persons with dementia will talk about their dog. The dog often becomes a topic of conversation that starts the socialization process.

Creation of a conceptual framework

This study also documented situations where a canine assistance must be considered with caution. The dyads without dogs provided reasons why dogs were not desirable in their home. The question of maintenance or daily care of the dog was the most predominant reason. Many caregivers in this group mentioned that their loved one often fell as the disease progressed. They indicated the fear of losing balance and falling when the dog is in the way. The research team has also observed that caregivers without dog in our study have a higher score on the Caregiver burden scale (indicating a higher burden) than people with an NSD and tend to have a higher proportion of Parkinson disease. In Parkinson's disease, walking becomes less automatic (Abou-Sharkh & Mayo, 2021). The person with this disease must make a greater effort and concentrate to maintain an efficient and safe gait. In our study, one of the five people who acquired a NSD had Parkinson's (39 years old) and had a mild dementia. She did not report that her dog kept her from losing her balance or that she fell. This suggests that at a mild stage of the disease the NSD may be protective for safe and effective walking. In our study, four of these five individuals had mild dementia and were younger than in the other two groups.

Based on this discussion and results obtained, the figure 2 proposes a conceptual framework of the usability of the NSD for caregivers living with a person with dementia. It suggests that the usability of the NSD involves five roles and four usages. Its usability is facilitated by 7 potential benefits and 6 considerations are important. Five recommendations are provided for the public aimed at increasing facilitators and decreasing obstacles to improve the NSD usability, as well as companion dogs.

Aim 3

We conducted a cost-effectiveness analysis associated with having canine assistance in the home of the community-dwelling person with dementia (e.g., costs related to dog acquisition/training, post-placement, costs savings; benefits measured in terms of quality of life for carers and those with dementia) and we could not validate our hypothesis as groups have statistically the same level of quality of life, medical expenses and lost of revenue due to their role of caregivers. There were some tendencies in terms of quality of life and the real cost of providing care to the person with dementia but to confirm those trends we would need to expand this study with more participants and maybe include only participants with a mild stage of dementia as it can help to reduce the variability in help needed and medical expenses.

Aim 4

To characterize the physical activity level sleep quality of participants with dementia, we asked them to wear a monitoring device during 7 consecutive days. Based on the results we cannot confirm that the level of exercise and the quality of sleep are better with a companion dog or a certified dementia dog than without a dog. However, in the interviews, we noticed that the NSD encourages moderate and vigorous-intensity physical activity in the routine of the person with dementia (it is trained for this) while the companion dog encourages more quiet walks and play in the house. Furthermore, they both can promote quality of the sleep and attends to awakenings. To address the discrepancy between those two results a larger study with a new design should be put in place. Measuring sleep and physical activity should be done multiple times during the year, preventing an impact from the weather and reducing the influence of an event out of the ordinary (e.g., a cold, vacations). It would also help to determine if people with a neuro service dog need less sleep than the other groups.

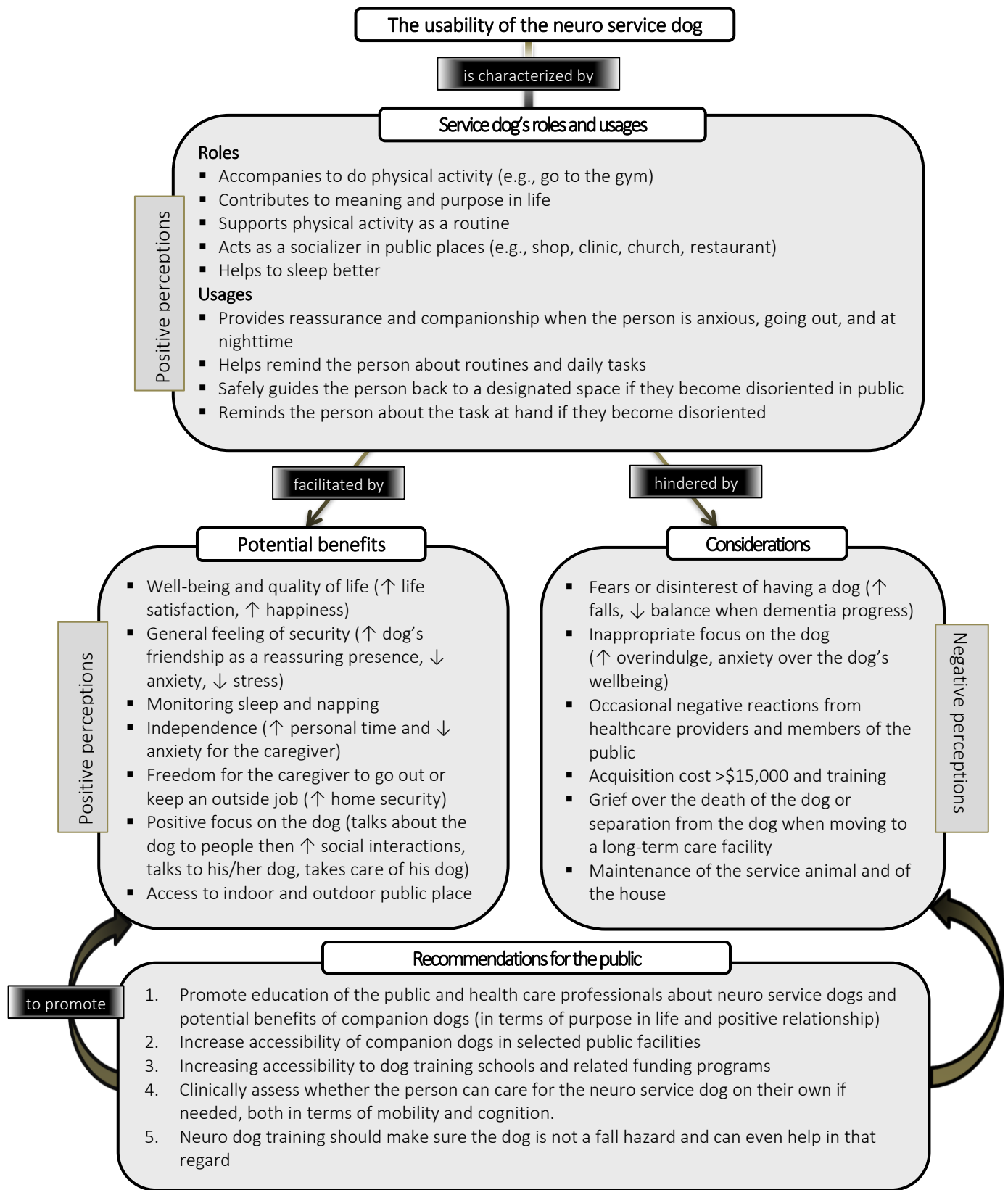


Figure 2. Usability of the neuro service dog for the caregiver living with a person with dementia: a proposed conceptual framework.

Methodological strengths, limitations and future research

The internal validity of the study is not fully met, since there were only 5 dyads in the NSD group as the training school closed in 2020 due to the Covid pandemic. We believe that if we had been able to recruit closer to 10 dyads, we could have claimed theoretical saturation because we would have maximised internal diversification of the sample (Krefting, 1991), for the case 1– dyads with NSD. This is also true for the case 3 – dyads with no dog – where we have to adapt the interview guide for people "who don't want a dog" when we were no longer able to reach "people on the dog school waiting list". Maybe with better internal diversification of those cases, the "unexpected usages of a dog" would have been less miscellaneous and would have resulted in other unique roles to a neuro service dog. With respect to the external validity of the study, the transferability of the data to a similar context is possible since we have provided exhaustive sociodemographic information for the three cases. Participants were recruited across Canada and USA and lived in a variety of home settings and dogs were from various sizes and types. Thus, we believe that the data can be generalized to a comparable geographic context. Regarding the external reliability of the study, we feel we achieved optimal consistency since we explained in detail the procedure for developing themes and sub-themes in the methodology section. Finally, concerning the internal reliability of the study, doing parallel coding of the interviews three times with two other evaluators ensured better confirmatory potential of the study results (Krefting, 1991).

Further research is needed to better document the evolution of NSD roles and usages over time, as well as the benefits and drawbacks. The results of the present study were cross-sectional, and data was collected between three and fourteen months following the acquisition of a NSD. Also, more participants with a NSD could have reduced results variability when measuring sleep quality, physical activity and economic impacts. The growing number of the dementia population and the products of this study can help to promote the training of NSD by convincing dog training schools to invest in this field and by persuading charitable organizations to support the acquisition of a NSD by those in needs. In accordance to national standards on management of animal-assisted human services (Human research standards organisation, 2022), the training a neuro service dog have the potential to aid people with dementia and their family caregiver.

Scientific presentations

Vincent, C., Dumont, F., Achou, B., Brown, C., Bremault-Phillips, S., Travis, B., Rivard, A., and Bourassa, J (2019). Dementia dogs and their impact on community-dwelling persons with mild to moderate dementia and their family caregivers. The 15th International conference of the Association for the Advancement of Assistive Technology in Europe. Bologna. Italy, 27-30 August, *Published in* Technology and disability, Volume 31, Supplement 1, 2019 <https://content.iospress.com/journals/technology-and-disability/31/s1>

Abstract

Background: Individuals with mild to moderate dementia, and their caregivers, may benefit from the support of a dementia dog. It falls into the category of cognitive aids (assistive technology for disabilities). It's a dog trained to provide cues (and sometimes reminders) and companionship. improve activity-levels and wayfinding, and enhance well-being and connection. There are very few schools that have a formal training program to train dementia dogs; we have found one dog schools in USA, one in Scotland and one in Australia. Since there is no scientific evidence addressing the efficacy of dementia dogs, our study proposes the following research objectives: 1- to examine the impacts of canine assistance on both the person with dementia and his/her caregiver (e.g., on engagement, socialization, well-being, activity levels, wandering, sense of meaning and purpose, quality of life, stress and health); 2-to conduct a cost-effectiveness analysis associated with having a canine assistance in the home of the person with dementia (e.g., costs related to dog acquisition and community training, postplacement, costs savings; benefits measured in terms of quality of life for caregivers and those with dementia); and 3-to examine the acceptance of canine assistance in public places in the prior 3 months from the caregivers' point of view (e.g. approachability situations and socialization experiences). Method: A comparative analysis of 3 'cases' is underway. Each case will be comprised of 20–40 dyads of a caregiver, person with mild to moderate dementia, and either (1) a companion dog, (2) a certified support dog, or (3) no dog. Data collection will include phone/Skype interviews with caregivers, a cost effectiveness analysis and observation at dog training schools. Phone questionnaires used are the Concern for the Care recipient's Well-Being (CCWB) and the Impact on the Caregiver's Social Life (ICSL) (two subscales of the Caregiver's Burden Scale). Online questionnaires used are the Adult social care outcomes toolkit (ASCOT), the Social care-related quality of life (SCRQoL), the ICEpop (Investigating Choice Experiments for the Preferences of Older People) and the CAPability measure for Older people (ICECAP-O). A qualitative thematic analysis of interviews and comparisons of the quantitative data across the 3 cases will be conducted. Key results: Preliminary results on canine assistance has a positive impact on the lives of persons with dementia and their caregivers (supporting engagement, quality of life, well-being of the dyads, and enabling the person with dementia to remain at home safely and the caregiver remain or return at work). Conclusion: With more results about canine assistance, it may be possible to advocate for the establishment of new training programs for certificated dementia dogs across Canada. Furthermore, positive results from the cost-effectiveness analysis and acceptance of the dementia dogs in public places will inform policymakers about the feasibility of funding certified dogs and to establish the associated public policies.

Vincent, C., *Rogers, M., Brown, C., Bremault-Phillips, S., Achou, B., Rivard, A., Dumont, F (2021). Impact of dementia dogs on community-dwelling persons with mild to moderate dementia and their family caregivers. Oral #75. 2nd COTEC-ENOTHE Congress. Occupational Therapy in Europe, Prague, September 15–18 <https://ot-europe2020.exordo.com/programme/presentation/1898>

Abstract

Individuals with mild to moderate dementia, and their caregivers, may benefit from the support of a dementia dog. It's a dog trained to provide cues (and sometimes reminders) and companionship, improve activity-levels and wayfinding, and enhance well-being and connection. Since there is no scientific evidence addressing the efficacy of dementia dogs at home, our study proposes the following research objectives: 1-to examine the impacts of canine assistance on both the person with dementia and his/her caregiver (e.g., on engagement, socialization, well-being, ADL); 2-to examine the acceptance of canine assistance in public places (e.g. approachability situations and socialization experiences). 3- to quantify level of physical activity and quality of sleep; and 4-to conduct a cost-effectiveness analysis associated with having a canine assistance in the home of the person with dementia (e.g., costs and benefits measured in terms of quality of life for caregivers and those with dementia). A comparative analysis of 3 'cases' is underway. Each case will be comprised of 20-30 dyads of a caregiver, person with mild to moderate dementia, and either (1) a companion dog, (2) a certified support dog, or (3) no dog.

Janvier : le mois de sensibilisation à la maladie d'Alzheimer. Pourquoi avoir choisi ce domaine de recherche, les maladies cognitives dont l'Alzheimer? Faculté de médecine, Université Laval, 30 janvier 2019, <http://www.fmed.ulaval.ca/faculte-et-reseau/a-surveiller/nouvelles/detail-dune-nouvelle/janvier-le-mois-de-sensibilisation-a-la-maladie-dalzheimer/>

Sharing results with participants and stakeholders

First, a document was made to inform primarily participants and but also stakeholders to present them the results in a way that was accessible and visually appealing. It was sent to all 56 caregivers who participated in the study. On the other hand, this summary was sent to stakeholders upon request. They all first received an infographic page about recommendations, specific tasks, potential benefits and considerations to have for the use of a neuro service dog.

The infographic page was sent to all provincial branches of the Alzheimer Society as well as the Alzheimer society of Canada.

Alzheimer Society of Canada
20 Eglinton Avenue West, 16th Floor
Toronto, ON M4R 1K8
Email: info@alzheimer.ca
Website: www.alzheimer.ca

Alzheimer Society of Alberta and Northwest Territories
#306, 10430 - 61 Avenue
Edmonton, Alberta T6H 2J3
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Web: www.alzheimer.ca/ab

Alzheimer Society of Calgary
800-7015 MacLeod Trail SW
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112-2719 Gladstone St.
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Alzheimer Society of Ontario
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Toronto, ON M4R 1K8
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Web: www.alzheimer.ca/on

Alzheimer Society of Prince Edward Island
166 Fitzroy St.
Charlottetown, PE C1A 1S1
Email: society@alzpei.ca
Web: www.alzheimer.ca/pei

Federation of Quebec Alzheimer Societies
507-460 rue Sainte-Catherine Ouest,
Montreal, QC H3B 1A7
Email: info@alzheimerquebec.ca
Web: www.alzheimer.ca/federationquebecoise

Alzheimer Society of Saskatchewan
301 - 2550 - 12th Ave.
Regina, SK S4P 3X1
Email: office@alzheimer.sk.ca
Web: www.alzheimer.ca/sk

Furthermore, it was also sent to partners situated in the Canada and United States that helped us with the recruitment.

Early Onset Dementia Alberta Foundation
54 Meadowview Dr.
Leduc, Alberta, T9E 6S4
Email: rep@eodaf.com
Web: www.eodaf.com

Alzheimer's Foundation of America
322 Eighth Avenue, 16th Floor
New York, NY 10001, USA
Email: info@alzfdn.org
Web: www.alzfdn.org

Family Caregiver Alliance
235 Montgomery Street Suite 930
San Francisco, CA 94104, USA
Email: info@caregiver.org
Web: www.caregiver.org

Dementia Society of America
188 N Main St,
Doylestown, PA 18901, USA
Email: info@dementiasociety.org
Web: www.dementiasociety.org

Finally, this information was also shared with dog training schools.

ASISTA Foundation
4530 Autoroute 440 Laval
Québec, H7T 2P7
Email: info@asista.ca
Web: <https://asista.ca/>

Canadian Canine Training
52111 Range Road 231,
Sherwood Park, T8B 1E5
Email: train@canadiancaninetraining.com
Web: <https://canadiancaninetraining.com/>

CARES, inc.
Canine Assistance, Rehabilitation, Education and Services
P.O. Box 314
Concordia, KS, 66901, USA
Email: cares.ks@sbcglobal.net
Web: <http://www.caresks.com/>

HopeHeels
Edmonton, Alberta
Email: info@HopeHeels.com
Web: <http://www.hopeheels.com/>

Mira Foundation
1820 Rang Nord-Ouest
Sainte-Madeleine QC J0H 1S0
Email: info@mira.ca
Web: <https://www.mira.ca/fr/>

National service dog
1286 Cedar Creek Rd.
Cambridge, ON N1R 5S5
Email: info@nsd.on.ca
Web: <https://nsd.on.ca/>

Thames Centre Service Dogs
23698 Sutherland Rd,
Mount Brydges, ON N0L 1W0
Email: TCSD@live.ca
Web: <https://caniandogs.com/thames-centre-service-dogs/>

Vancouver Island Compassion Dogs Society
7061 Ladner Trunk Road, Delta BC, V4K 3N3
Email: info@bcguidedog.com
Web: <https://bcandalbertaguidedogs.com/our-dogs/ptsd-service-dogs/>

Wilderwood service dogs
1319 Tuckaleechee Trail
Maryville, TN 37803
Email: wilderwood@charter.net
Web: <https://wilderwood.org/>

The organizations that requested a copy of the summary of the results are the Alzheimer Society of B.C., the Alzheimer society of Canada, the Mira Foundation, and the Dementia Society of America.

Summary of the main results

The impact of service dogs on the lives of people with mild to moderate dementia living with their caregiver

Summary of results for participants



Cirris



Acknowledgements

We would like to thank all those who contributed to the realization of this project and in particular the study **participants for their generosity and support.**

Authors of this summary

- **Frédéric Dumont**, PhD, Research Coordinator, Cirris
- **Émilie Cloutier-Debaque**, student, School of Psychology, Université Laval
- **Claude Vincent**, PhD, erg, Principal Researcher, Cirris, Professor, Department of Rehabilitation, Université Laval

Support for the recruitment of participants

- Provincial Associations of the Alzheimer Society of Canada
- CIUSSS de la Capitale Nationale
- CenterWatch

Financial support for this project provided by:

Société Alzheimer Society

C A N A D A

Participants



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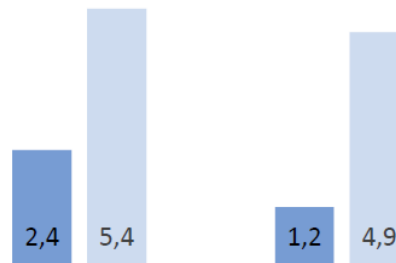
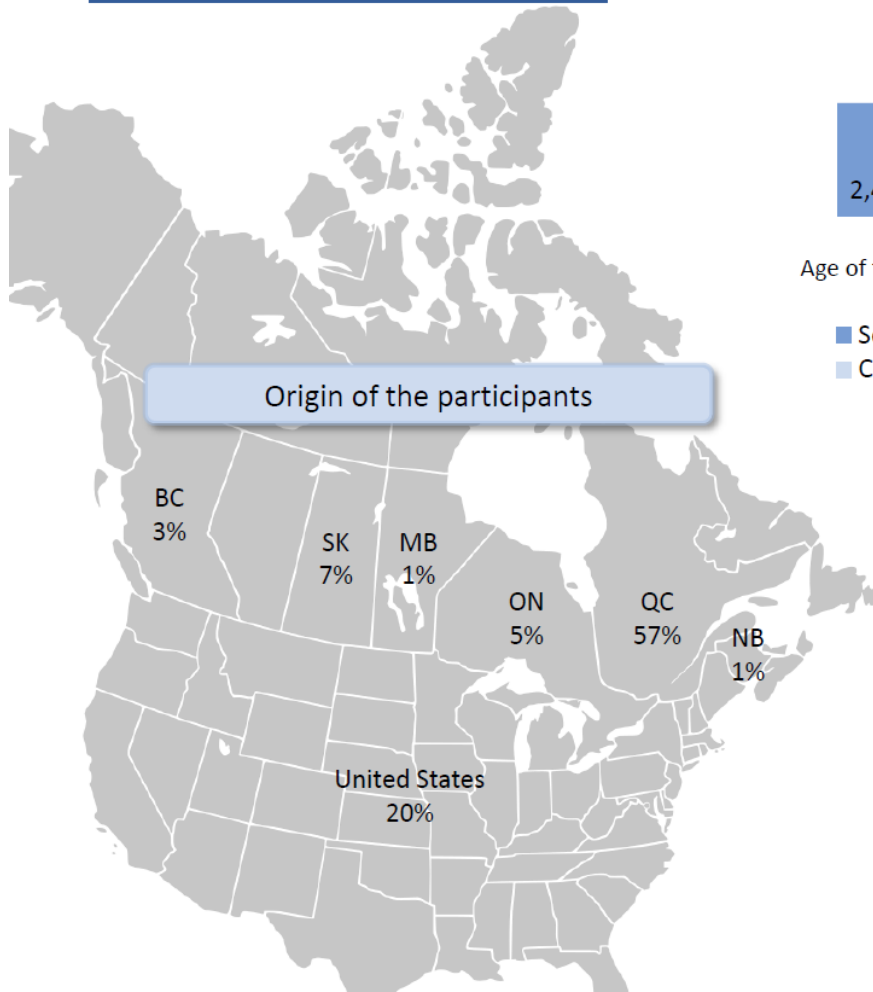
From 2019 to 2021, 112 participants were recruited, forming 56 pairs of people with dementia and family caregivers. Of these 56 pairs, 28 had a companion dog, 23 did not have a dog, and 5 had a service dog.

The objective of this project was to examine the impact of canine assistance on the person with dementia living with their family caregiver.

You will find a summary of the results that emerged from this study.

Demographic characteristics

This section presents the characteristics of **all** participants






Service dogs were younger and adopted for less time than companion dogs

Age of the dog (years) Years since its acquisition

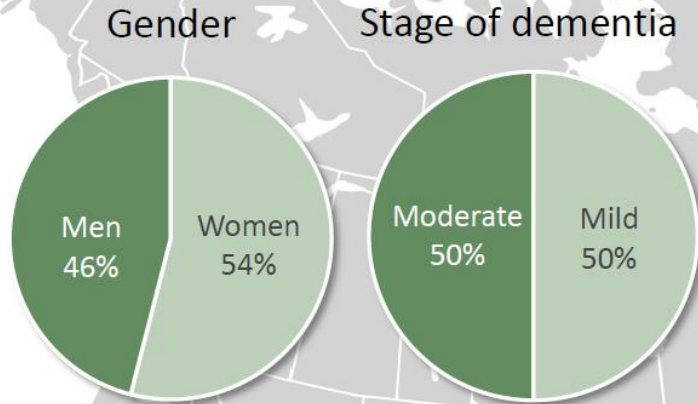
■ Service dog ■ Companion dog

35% of participants had another animal

- 24%** Had a cat 
- 9%** Had another dog 
- 5%** Had another type of animal 

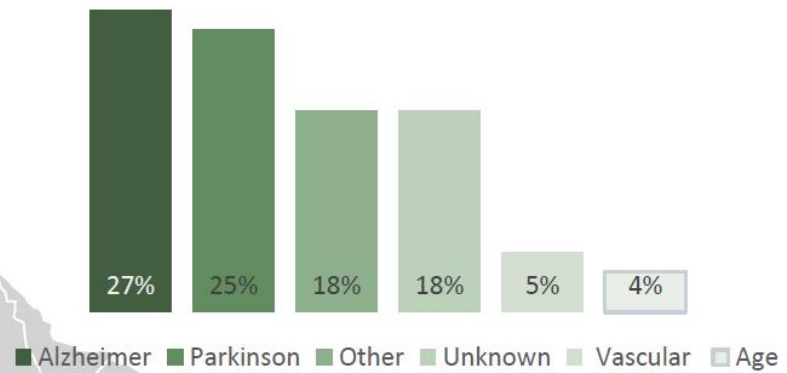
Demographic characteristics

This section presents the main characteristics of participants with **dementia**.

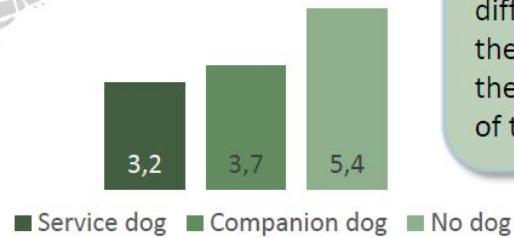


Note that the 5 participants with service dogs were younger on average than those in the other groups, but had been dementia for as long as the others.

Types of dementia



Number of years since diagnosis



Here, there is no statistical difference between the groups due to the great variability of the responses

Demographic characteristics

This section presents the main characteristics of caregivers.

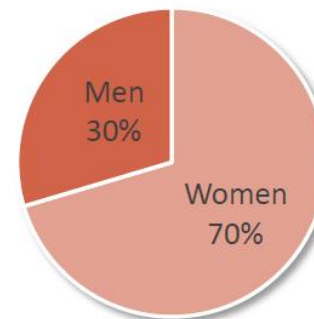
Relationship with the person with dementia

89%
Spouse

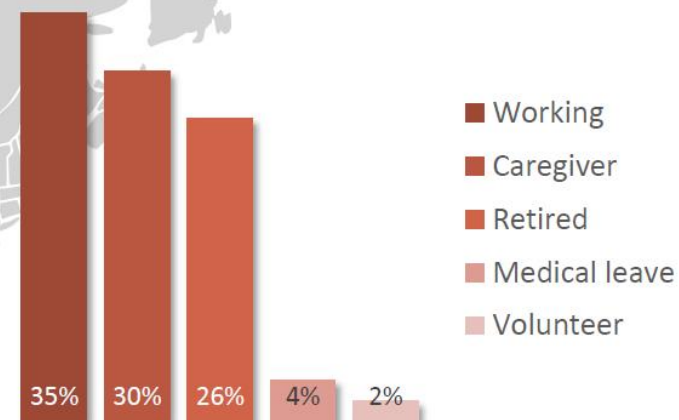
9%
Children

2%
Siblings

Gender



Main occupation



Engagement
Physical activity
Orientation
Socialization



All of the groups talked about the commitment that the dog confers to the person with dementia. For some, it is one of the last roles that gives meaning to their life at home. This was noted more among those with a companion dog and those without a dog. While those with a service dog talked more about what the dog does for them.

“I’d literally be lost somewhere without mine [neuro service dog]. God, I don’t know where I would be. And today, she basically dragged me to kickboxing and dragged me home. It’s because she knows the routine and that’s what we do.”

“I would say that when I’m not around he’s very good at taking care of the dog. He is able to recognize his needs... It is a non-verbal communication that has been established over time and I would say that it is beautiful to see, myself I am amazed at that.” [companion dog]

Those with service dogs gave twice as many examples of socialization as in the companion dog group, as they are allowed inside public buildings.

“ The people at church are very impressed with her [the dog], because I sing in the choir, and she has to be right there with me, so she’s in the choir when we’re performing. ” [Neuro service dog]

One of the most important roles of the dog is to provide company. This was reported similarly in both groups with dogs. Among those without dogs, many did not seek their company.

“So, she’s there, hum... so she’s my protection, she’s my companion, she makes me be more responsible with things, like I have a job to do with her, which keeps my mind going somewhat.” [Neuro service dog]

The benefits of having a dog

A decrease in stress and anxiety was reported by most participants having dogs.

“ He has a lot of suffering with anxiety and has not been able to, his body can't handle the anti-anxiety medication very well. So we were looking for a different way of coping with anxiety helping with confidence. So he was a very confident man but he has lost his confidence. When I see him out with the dog. His shoulders are back and he is walking with a purpose. I noticed it. ”

[Neuro service dog]

The independence that dogs bring was reported by everyone with a service dog, most people with a companion dog, but few people without a dog.

“ Getting back to what you have asked. If I have to leave and get to my daughter's house or to do errands or something, I feel more comfortable that he is with Vicki like a companion, and that she is not by herself. That was one of the reasons why she wanted me to quit work, because she was alone by herself and bored and things like that at home for 12 hours by herself. ” [Neuro service dog]

The majority of those with a dog (service or companion dog) mentioned that the dog can help them sleep or go back to sleep, which can alleviate some of the caregiver's tasks

“ Oh yes! I definitely sleep better when the dog is lying next to me. It's like a feeling of security.” [Neuro service dog]

Disadvantages, inconveniences and obstacles of having a dog

Time and cost are also considerations when acquiring a service dog. Depending on the dog school, the cost can be paid in part by donations, but it is still a significant investment of time and money.

“...well it took the best part of a year and a half to two years before they trained him because when we went down there to visit, we wanted to see the progress they come along ”
[Neuro service dog]

“ So I kept searching and I found a couple. One in Vancouver and then this one in Winnipeg and we went with them. Now to have a dog trained, it is pricey. We paid \$25,000, which is a lot.”
[Neuro service dog]

The two most common inconveniences for people who **do not have a dog** are the daily care to the dog (64%) and the fear/disinterest in dogs (50%).

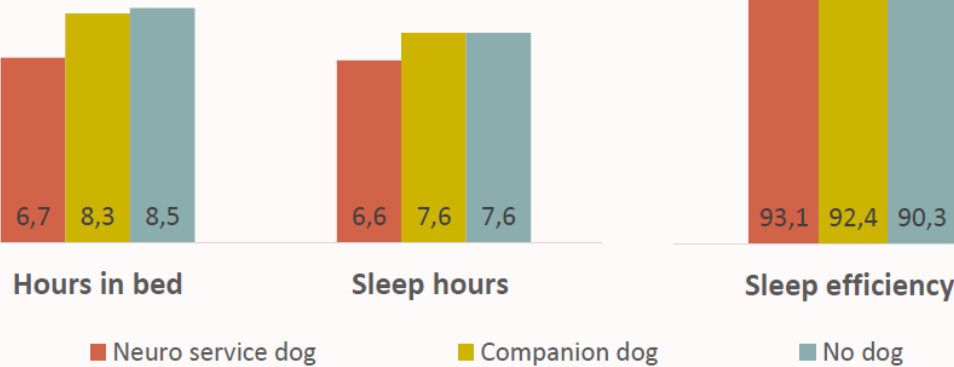
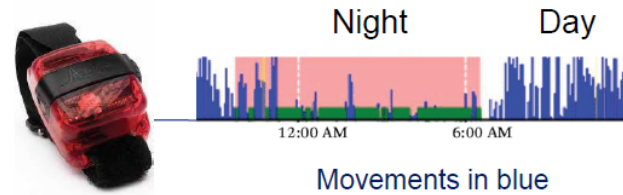
For people with a **service dog**, it is more about the negative reaction that some people may have towards the dog (60%) and having to face the separation of the dog one day (60%).

While among people with a **companion dog**, the main concerns are having to deal with the separation of the dog (63%) and the daily care to the dog (48%)

Many people report their fears about the increased risk of falls in the presence of a dog

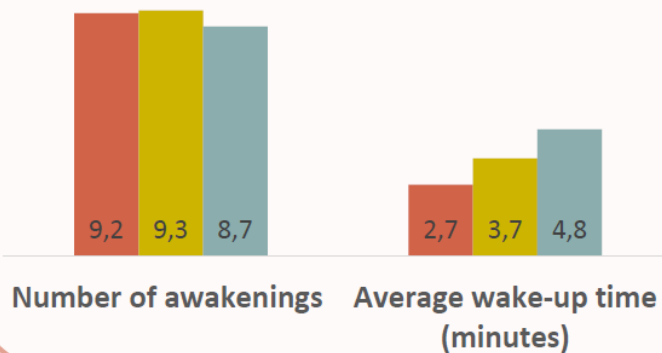
“ The only issue I had was, being that he was not a service dog or trained to be a service dog, I was scared that he would trip my wife. Being that she had dementia, she'd forget that he's around and he'd get in between her legs or something, and trip her. ” [Companion dog]

Sleep measured by the activity monitor



In our study, people with dementia wore a watch (activity monitor) for 7 days and 7 nights.

In our study, people with a neuro service dog (red bars) appear to need less sleep because they spend less time in bed and because their sleep efficiency was similar. We recommend that a larger study examine this point.



Participants have the same number of awakenings per night on average and it cannot be concluded that the time of awakening is different due to the high variability observed.

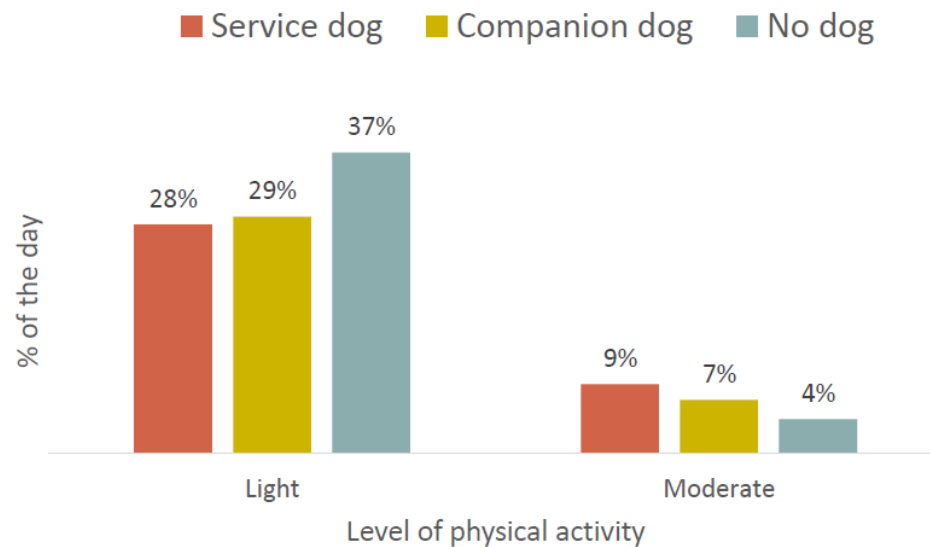
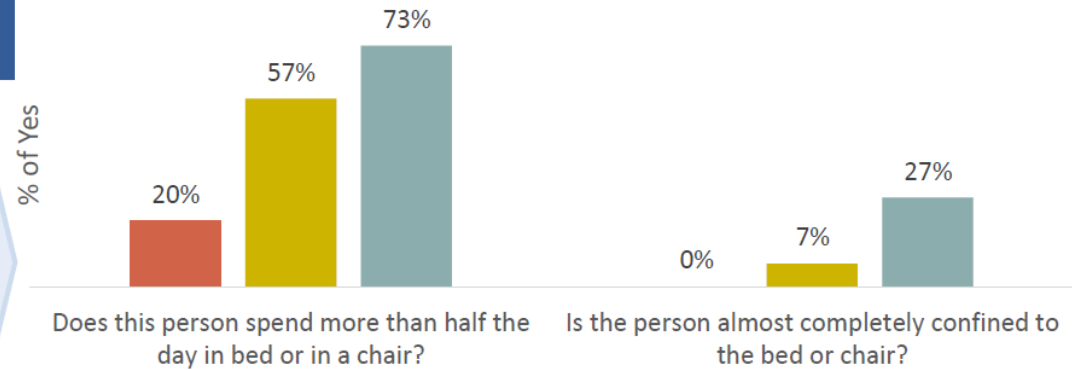
Time sited or in bed versus physical activity

In the group with a neuro assistance dog, caregivers tended to notice less that their loved one spent more than half (or almost all) of the day sitting or lying down.



The activity monitor was able to measure that people who do not have a dog spend a larger portion of their day doing light activity (e.g. quiet standing activity).

On the other hand, those with dogs seem to spend about twice as much time as those without dogs doing moderate intensity activities (e.g. brisk walking).



Quality of life

The two questionnaires that measured quality of life show no difference between the groups, indicating that having a dog does not increase or decrease the aspects of quality of life that were studied.

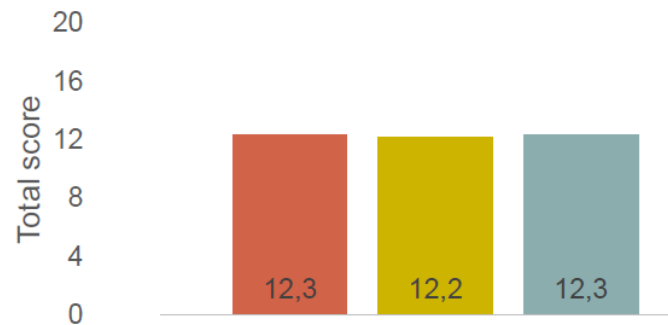
ICECAP (ICEpop CAPability) is an instrument used with elderly populations to measure well-being according to 5 aspects: attachment (love/friendship), thinking about the future, rewarding activities, pleasure and independence. Total scores were similar between groups.

A total score of 12 corresponds to a moderate level where respondents had several aspects that were unsatisfied.

ASCOT (Adult Social Care Outcomes Toolkit) is a questionnaire, available only in English, which measures the quality of life related to social care among caregivers by measuring 7 aspects of life (feeling supported, social participation, time for oneself, etc.). A score of 7 to 13 indicates that improvements are needed in some aspect of people's lives.

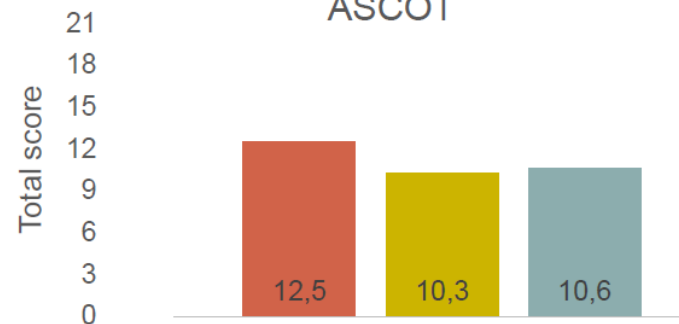
Although there is no statistical difference, it is possible that more participants with a neurological service dog could confirm an increase in quality of life. For this, more service dog training schools will have to start offering dogs for this clientele.

ICECAP



■ Neuro service dog ■ Companion dog ■ No dog

ASCOT



Caregiver Burden

Caregiver Burden

This questionnaire gives us information on the burden that the person feels in his or her role as a caregiver. The higher the total, the more burden the person feels (a score of 34 being a moderate level of burden).

The total score tells us that the caregivers in the **neuro service dog** group tend to feel a **lighter** burden.

When we try to identify why, we notice that there are two questions where we find a significant difference between groups. These are the questions:

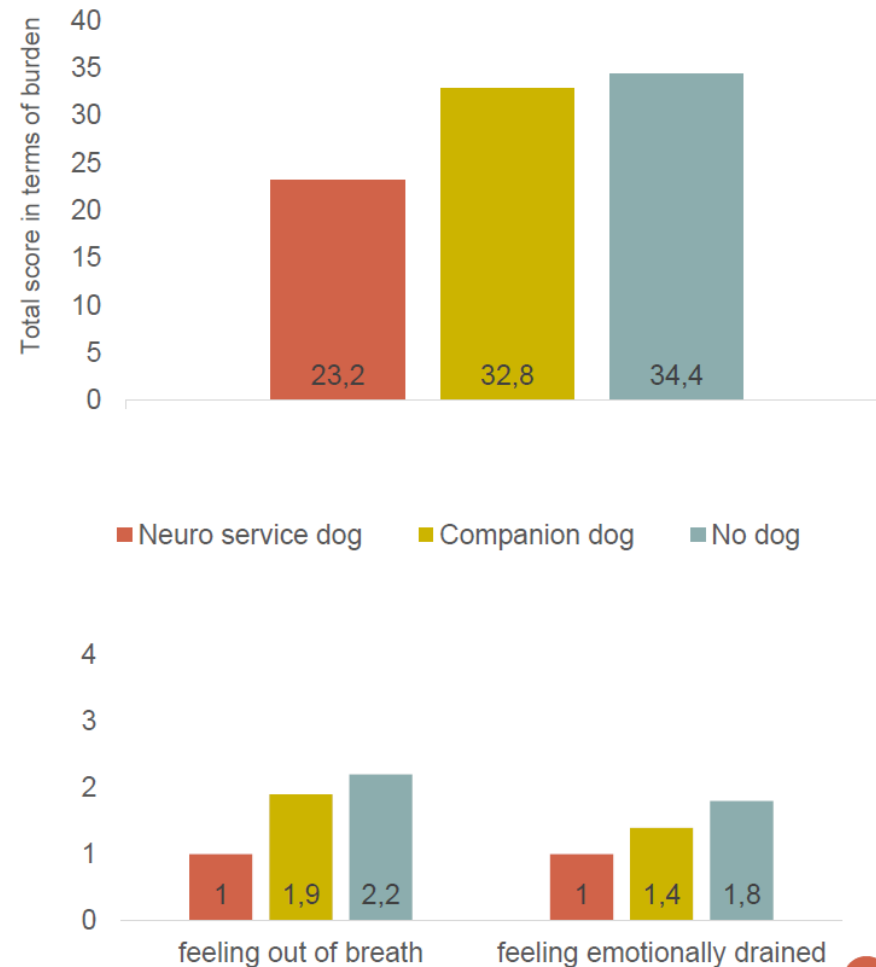
Do you ever feel out of breath?
Do you ever feel emotionally drained?


It is possible that the neuro service dog will help caregivers in this respect.

Scale:

1=Never, 2=From time to time

3=Somewhat often and 4=Very often





L'impact des chiens d'assistance
sur la vie des personnes présentant
une démence légère à modérée
vivant avec leur proche-aidant

Sommaire des résultats pour les participants



Cirris



Remerciements

Nous tenons à remercier tous ceux qui ont contribué à la réalisation de ce projet et en particulier **les participants de l'étude pour leur générosité et leur support.**

Auteurs de ce sommaire

- **Frédéric Dumont**, PhD, Coordonnateur de recherche, Cirris
- **Émilie Cloutier-Debaque**, étudiante, École de psychologie, Université Laval
- **Claude Vincent**, PhD, erg, Chercheure principale, Cirris Professeure, Département de réadaptation, Université Laval

Support pour le recrutement des participants

- Associations provinciales de la Société Alzheimer du Canada
- CIUSSS de la Capitale Nationale
- CenterWatch

Support financier pour ce projet fourni par:

Société Alzheimer Society

C A N A D A

Participants



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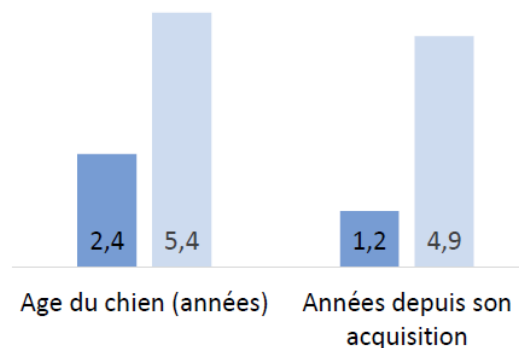
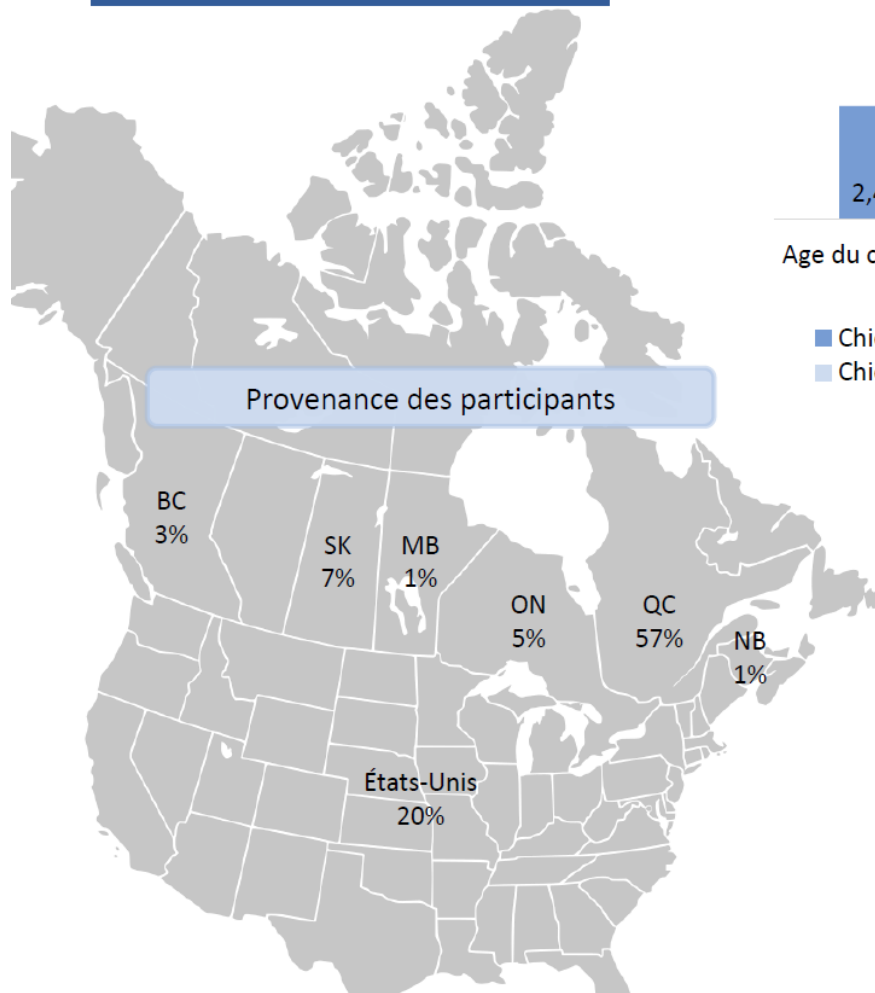
De 2019 à 2021, 112 participants ont été recrutés, formant 56 paires de personnes ayant des troubles cognitifs et de proches aidants. De ces 56 paires, 28 avaient un chien de compagnie, 23 n'avaient pas de chien et 5 avaient un chien d'assistance neurologique.

L'objectif de ce projet était d'examiner les impacts de l'assistance canine dans la vie de la personne avec une démence vivant avec son proche-aidant.

Vous retrouverez un sommaire des résultats qui ressortent de cette étude.

Caractéristiques démographiques

Cette section présente les caractéristiques concernant l'ensemble des participants



Les chiens d'assistance étaient plus jeunes et adoptés depuis moins longtemps que les chiens de compagnie

■ Chien d'assistance
■ Chien de compagnie

35% des participants avaient un autre animal

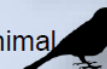
24%
Avaient un chat



9%
Avaient un autre chien

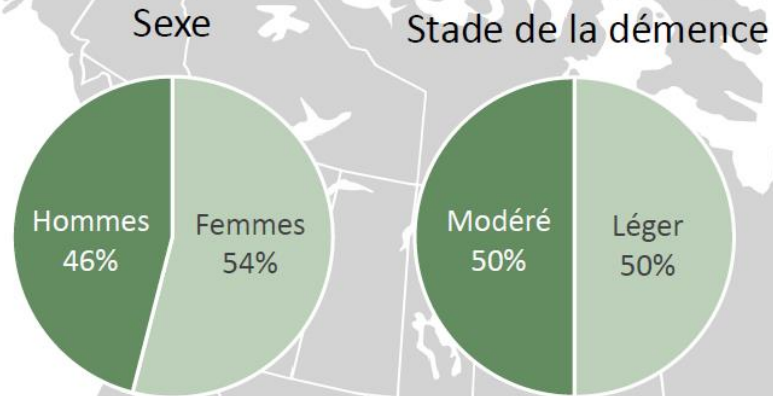


5%
Avaient un autre type d'animal



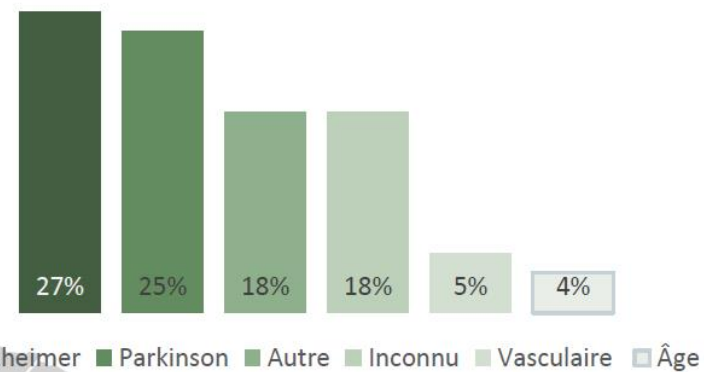
Caractéristiques démographiques

Cette section présente les principales caractéristiques des participants ayant une forme de **démence**.

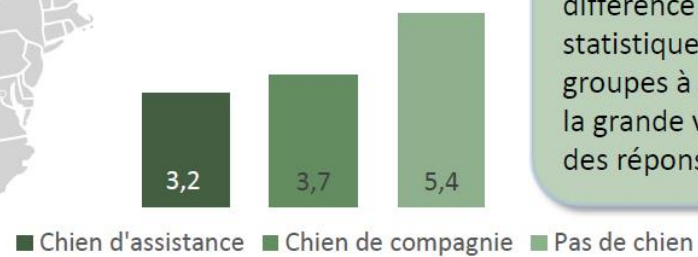


Il est à noter que les 5 participants ayant un chien d'assistance étaient plus jeunes en moyenne que ceux des autres groupes, mais qu'ils étaient atteints de démence depuis aussi longtemps que les autres

Formes de démence



Nombre d'années depuis le diagnostic



Ici, il n'y a pas de différence statistique entre les groupes à cause de la grande variabilité des réponses

Caractéristiques démographiques

Cette section présente les principales caractéristiques des proches aidants.

Lien avec la personne ayant une démence

89%

Époux(se)

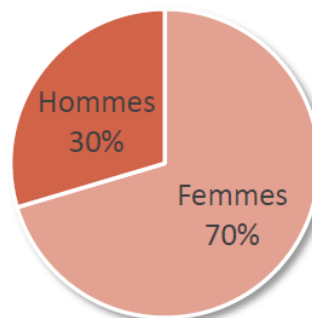
9%

Enfants

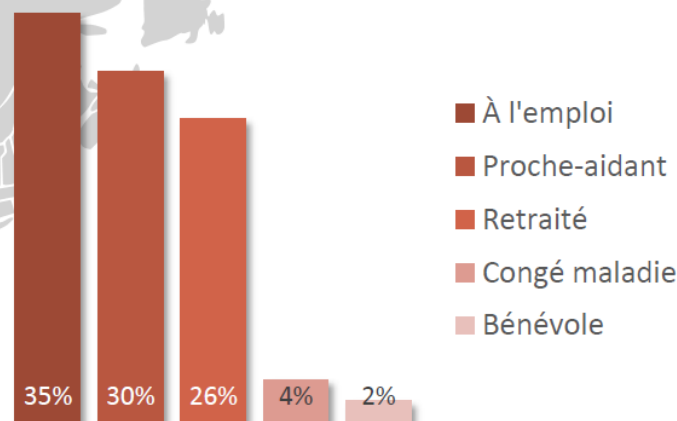
2%

Frères/soeurs

Sexe



Occupation principale



Engagement
Activité physique
Orientation
Socialisation



Tous les groupes ont parlé de l'engagement que le chien confère à la personne avec une démence. Pour certains, c'est l'un des derniers rôles qui donne un sens à leur vie à la maison. Ceci a été davantage relevé chez ceux ayant un chien de compagnie et ceux n'ayant pas de chien. Tandis que ceux ayant un chien d'assistance ont plus parlé de ce que le chien fait pour eux.

« Je serais littéralement perdu quelque part sans le mien [**Chien d'assistance neurologique**]. Mon Dieu, je ne sais pas où je serais. Et aujourd'hui, elle m'a pratiquement traîné au kickboxing et m'a ramené à la maison. C'est parce qu'elle connaît la routine et c'est ce que nous faisons. »

« Je dirais que quand je ne suis pas là, il est très doué pour s'occuper du chien. Il est capable de reconnaître ses besoins. ... c'est une communication non verbale qui s'est établie au fil du temps et je dirais que c'est beau à voir, moi-même je suis étonnée de ça. » [**Chien de compagnie**]

Ceux ayant des chiens d'assistance ont donné deux fois plus d'exemple de socialisation que dans le groupe de chiens de compagnie, car ils sont autorisés à l'intérieur des bâtiments publics.

« Les gens à l'église sont très impressionnés par elle [la chienne], parce que je chante dans la chorale, et elle doit être juste là avec moi, donc elle est dans la chorale quand nous jouons. » [**Chien d'assistance neurologique**]

Un des rôles les plus importants du chien est d'offrir de la compagnie. Ceci a été rapporté de façon similaire dans les deux groupes ayant des chiens. Chez ceux n'ayant pas de chien, plusieurs ne recherchaient pas leur compagnie.

« Donc, elle est là, hum... donc elle est ma protection, elle est mon compagnon, elle me rend plus responsable des choses, comme si j'avais un travail à faire avec elle, ce qui me permet de garder un peu l'esprit en éveil. » [**Chien d'assistance neurologique**]

Les avantages d'avoir un chien

Une diminution du stress et de l'anxiété a été mentionnée par la plupart des participants ayant des chiens.

« Il souffre beaucoup d'anxiété et n'a pas pu, son corps ne supporte pas très bien les médicaments contre l'anxiété. Nous avons donc cherché un moyen différent de gérer l'anxiété en aidant à la confiance. C'était un homme très confiant, mais il a perdu confiance en lui. Quand je le vois dehors avec le chien. Ses épaules sont en arrière et il marche avec un but. Je l'ai remarqué. »
[Chien de compagnie]

L'indépendance qu'apporte le chien a été rapportée par tous ceux ayant un chien d'assistance, la plupart de ceux ayant un chien de compagnie, mais par peu de gens n'ayant pas de chien.

« Pour en revenir à ce que vous avez demandé. Si je dois partir et me rendre chez ma fille ou faire des courses ou autre chose, je me sens plus à l'aise si elle est avec le chien, comme un compagnon, elle n'est pas toute seule. C'est l'une des raisons pour lesquelles elle a voulu que je quitte le travail, parce qu'elle était seule, qu'elle s'ennuyait à la maison pendant 12 heures toute seule. » [Chien d'assistance neurologique]

La majorité de ceux ayant un chien (d'assistance ou de compagnie) ont mentionné que le chien peut aider à dormir ou se rendormir ce qui peut alléger certaines tâches du proche aidant.

« Oh oui! Je dors définitivement mieux quand le chien est allongé à côté de moi. C'est comme un sentiment de sécurité. » [Chien d'assistance neurologique]

Inconvénients, désagréments et obstacles d'avoir un chien

Le temps et les coûts sont à considérer lors de l'acquisition d'un chien d'assistance. Dépendamment des écoles de chien, le coût peut être en partie payé par des dons, mais cela reste un investissement de temps et d'argent important.

« ...eh bien cela a pris la meilleure partie d'un an et demi à deux ans avant qu'ils ne l'entraînent, parce que lorsque nous sommes allés là-bas pour visiter, nous voulions voir les progrès et le chien qu'ils avaient entraîné. »

[Chien d'assistance neurologique]

« J'ai donc continué à chercher et j'en ai trouvé deux. Une à Vancouver et une autre à Winnipeg, et on est allé avec eux. Maintenant, pour faire dresser le chien, c'était cher. Nous avons payé 25 000 dollars canadiens, ce qui est beaucoup. »

[Chien d'assistance neurologique]

Les deux inconvénients les plus souvent relevés chez les personnes qui n'ont **pas de chien** sont les soins quotidiens qu'il faut apporter au chien (64%) et les peurs/désintérêts envers les chiens (50%).

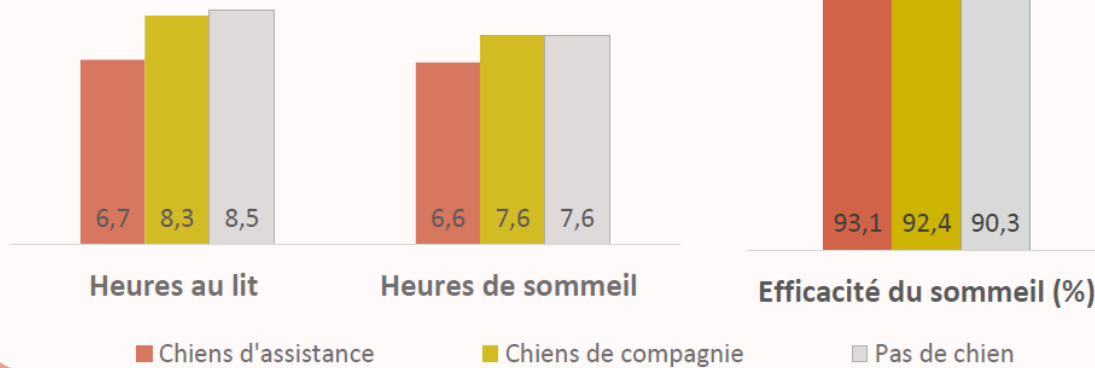
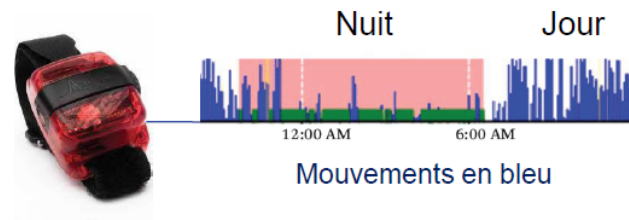
Chez les personnes ayant un **chien d'assistance neurologique** il s'agit plutôt de la réaction négative que certaines personnes peuvent avoir par rapport au chien (60%) et de devoir faire face un jour avec la séparation du chien (60%).

Tandis que chez les gens qui ont un **chien de compagnie**, les principales préoccupations sont de devoir faire face un jour avec la séparation du chien (63%) et les soins quotidiens qu'il faut apporter au chien (48%)

Plusieurs personnes rapportent leurs craintes par rapport à l'augmentation des risques de chutes en présence d'un chien.

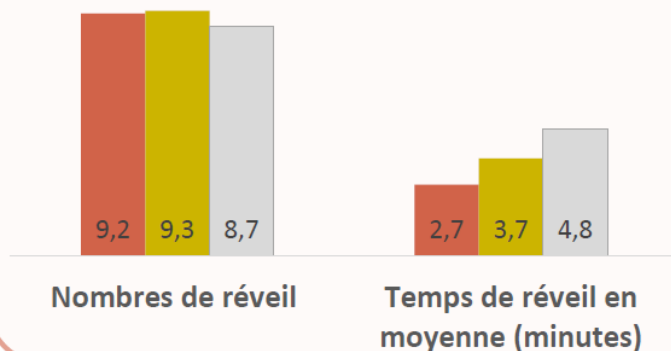
« Le seul problème que j'ai eu, c'est que comme il n'était pas un chien d'assistance et qu'il n'avait pas été dressé pour l'être, j'avais peur qu'il fasse trébucher ma femme. Comme elle est atteinte de démence, elle oublierait qu'il est là et il se mettrait entre ses jambes ou autre, et la ferait trébucher. » [pas de chien]

Sommeil mesuré par le moniteur d'activité



Dans notre étude, les personnes avec démence ont porté une montre (moniteur d'activité) pendant 7 jours et 7 nuits.

Les personnes ayant un chien d'assistance neurologique (barres rouges) semblent avoir besoin de moins de sommeil car elles passent moins de temps au lit et elles ont un sommeil tout aussi efficace que les autres. Nous conseillons qu'une étude de plus grande envergure se penche sur ce point.



Les participants ont le même nombre de réveils par nuit en moyenne et on ne peut conclure que le temps de réveil est différent à cause de la trop grande variabilité observée.

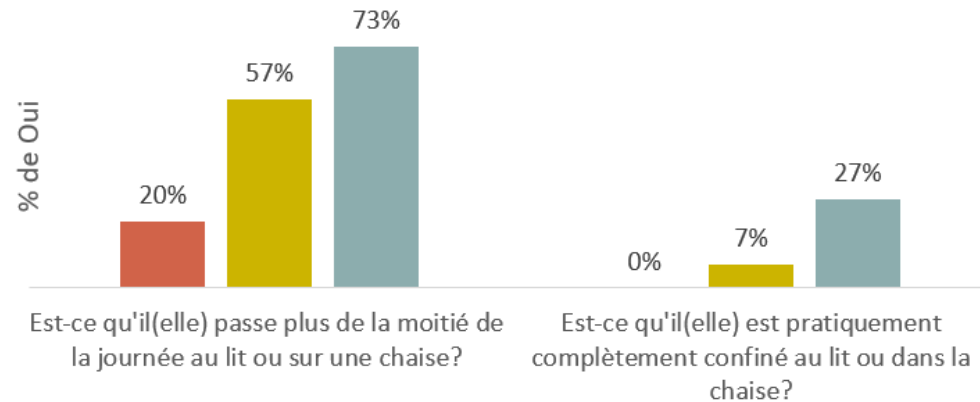
Temps passé assis ou au lit versus l'activité physique

Dans le groupe ayant un chien d'assistance neurologique, les proches aidants ont tendance à remarquer moins que leur proche passe plus de la moitié (ou la presque totalité) de la journée assis ou couché.

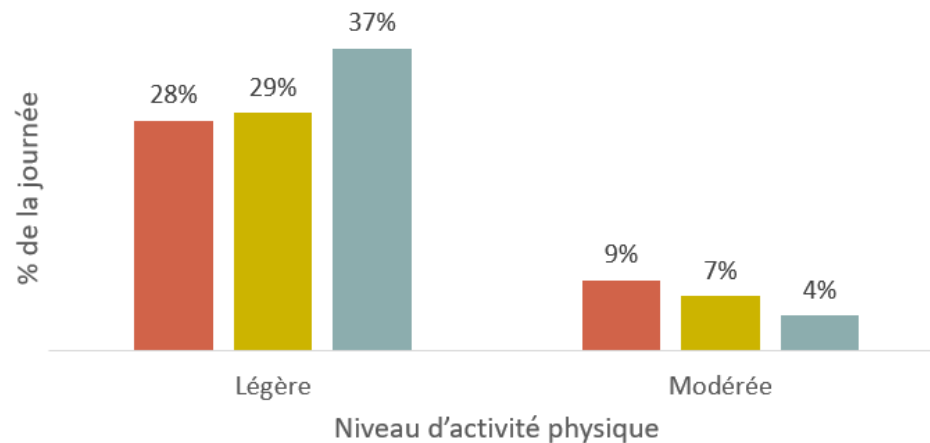


Le moniteur d'activité a pu mesurer que les personnes qui n'ont pas de chien passent une plus grande portion de leur journée à faire de l'activité légère (ex. activité calme debout).

En contre partie, ceux ayant un chien semble passer environ le double de temps que ceux qui n'en ont pas à faire de l'activités d'intensité modérée (ex. marcher rapidement).



■ Chien de service ■ Chien de compagnie ■ Pas de chien



Qualité de vie

Les deux questionnaires qui mesuraient la qualité de vie ne démontrent aucune différence entre les groupes nous indiquant que le fait d'avoir un chien n'augmente pas ni ne diminue les aspects de la qualité de vie qui étaient étudiés.

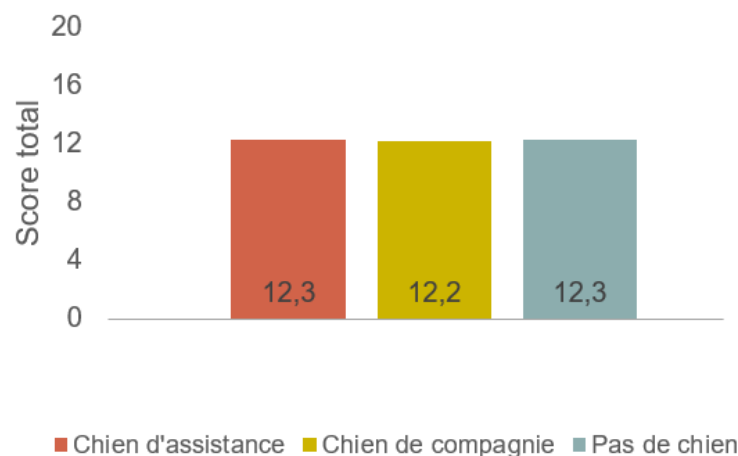
ICECAP (ICEpop CAPability) est un instrument utilisé avec des populations âgées pour mesurer le bien-être selon 5 aspects: l'attachement (amour/amitié), penser au futur, activités valorisantes, le plaisir et l'indépendance.

Les scores totaux étaient semblables entre les groupes. Un score total de 12 correspond à un niveau modéré où les répondants avaient plusieurs aspects qui étaient peu satisfait.

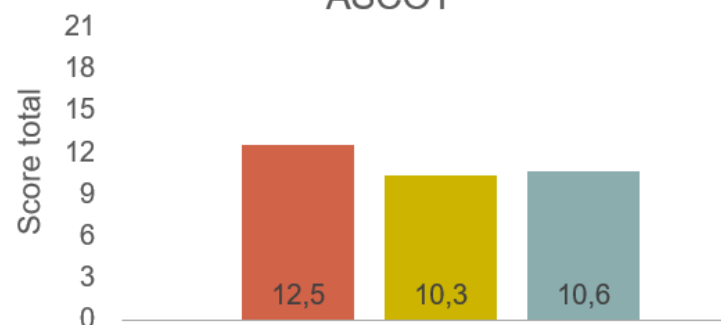
ASCOT (Adult Social Care Outcomes Toolkit) est un questionnaire, disponible seulement en anglais, qui mesure la qualité de vie liée aux soins sociaux chez les proches-aidants en mesurant 7 aspects de la vie (se sentir supporté, participation sociale, temps pour soi, etc.). Un score de 7 à 13 indique que des améliorations sont nécessaires dans certains aspects de la vie des gens.

Bien qu'il n'y ait pas de différence statistique, il est possible qu'un plus grand nombre de participants ayant un chien d'assistance neurologique puisse confirmer une augmentation de la qualité de vie. Pour cela, plus d'école d'entraînement de chien d'assistance neurologique devront commencer à offrir des chiens pour cette clientèle.

ICECAP



ASCOT



Fardeau du proche aidant

Fardeau du proche aidant

Ce questionnaire nous renseigne sur le poids que ressent la personne dans son rôle de proche aidant. Plus le total est élevé et plus la personne ressent ce fardeau (un score de 34 étant un niveau modéré de fardeau).

Le score total nous indique que les proches aidants du groupe avec **chien d'assistance** ont tendance à ressentir un fardeau **plus léger** que les autres groupes.

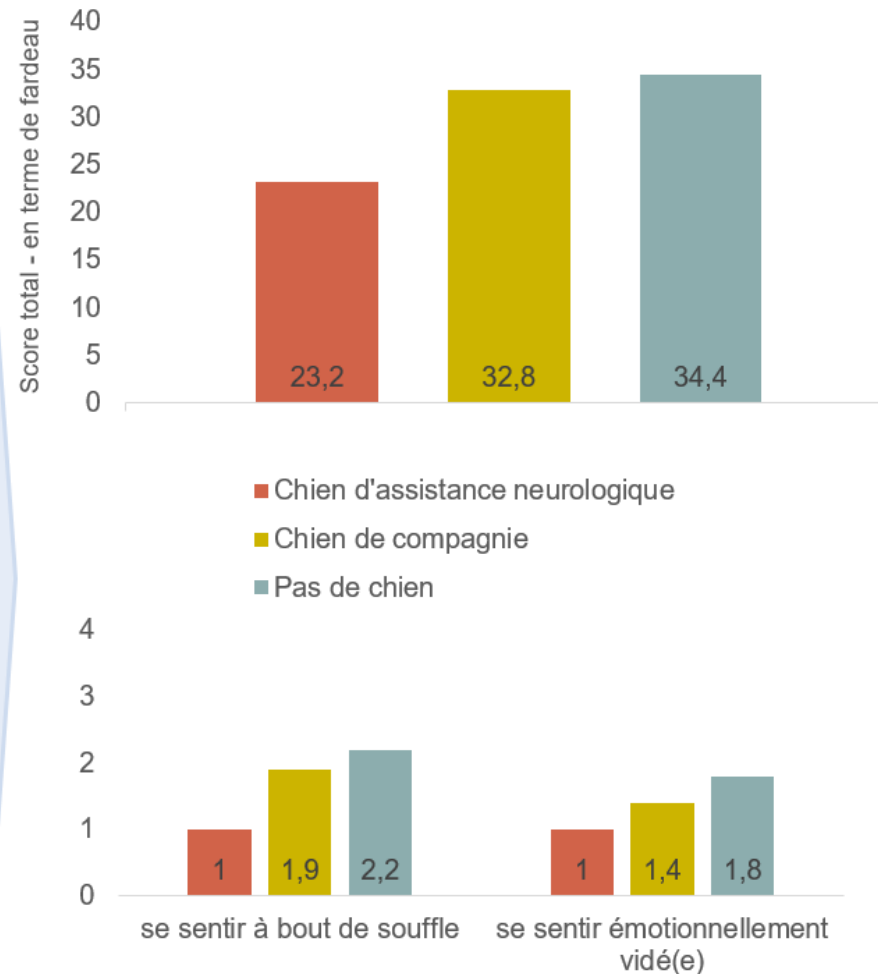
Lorsqu'on cherche à identifier pourquoi, on remarque qu'il n'y a que deux questions où l'on retrouve une différence significative entre les groupes. Il s'agit des questions:

- Vous arrive-t-il de vous sentir à bout de souffle?
- Vous arrive-t-il de vous sentir émotionnellement vidé(e)?

Il est possible que le chien d'assistance vienne soulager le proche aidant à ce niveau.

Échelle:

1=Jamais, 2=De temps en temps,
3=Assez souvent et 4=Très souvent



RECOMMENDATIONS

to help families who would like to acquire a neuro service dog for a loved one with dementia

Claude Vincent's research team, Cirris, Université Laval.

The goal of this project was to examine the impacts of dog assistance on both the person with mild to moderate cognitive impairment and their family caregiver. From 2019 to 2021, 112 participants were recruited, forming 56 pairs of people with cognitive impairment and family caregivers. Of these 56 pairs, 28 had a companion dog, 23 did not have a dog, and 5 had a neuro service dog. Acquisition of a neuro service dog was done through schools that can issue a public access certificate (Wilderwood service dogs in US and MSAR service dogs in Canada).

Soci t  Alzheimer Society

CANADA



Source: The Ashland NEWS

RECOMMENDATIONS

1. Promote education of the public and health care professionals about neuro service dogs and potential benefits of companion dogs (in terms of purpose in life and positive relationship)
2. Increase accessibility of companion dogs in selected public facilities
3. Increasing accessibility to dog training schools and related funding programs
4. Clinically assess whether the person is able to care for the neuro service dog on their own if needed, both in terms of mobility and cognition.
5. Neuro dog training should make sure the dog is not a fall hazard and can even help in that regard

Added value of the neuro service dog compared to a companion dog

The neuro service dog

Accompanies you to do physical activity (e.g. go to the gym)

Acts as a socializer in public places (e.g. shop, airport, clinic, church, restaurant)

Helps you sleep better

Contributes to meaning and purpose in life

Helps guide the person safely through the environment

Specific tasks

Provides reassurance and companionship when the person is anxious, going out, and at night time

Helps remind the person about routines and daily tasks

Safely guides the person back to a designated space if they become disoriented in public

Reminds the person about the task at hand if they become disoriented

Potential benefits:

- Access to indoor and outdoor public places
- Freedom for the caregiver to go out or keep an outside job
- Well-being and quality of life
- Positive focus on the dog (talks about the dog to people during interactions, takes care of his dog, etc.)
- Better routine
- Reduced stress
- Sleep monitoring

Considerations:

- Acquisition cost >\$15,000
- Time required for acquisition and training
- Occasional negative reactions from healthcare providers and members of the public
- Grief over the death of the dog or separation from the dog when moving to a long-term care facility
- Inappropriate focus on the dog (e.g., anxiety over the dog's wellbeing)

RECOMMANDATIONS

pour aider les familles qui voudraient acquérir un chien d'assistance neurologique pour un proche avec de la démence.

Équipe de recherche de Claude Vincent, Cirris, Université Laval.

L'objectif de ce projet était d'examiner les impacts de l'assistance d'un chien à la fois sur la personne ayant un trouble cognitif léger à modérer et sur leur proche-aidant. De 2019 à 2021, 112 participants ont été recrutés, formant 56 paires de personnes ayant des troubles cognitifs et de proches aidants. De ces 56 paires, 28 avaient un chien de compagnie, 23 n'avaient pas de chien et 5 avaient un chien d'assistance neurologique. L'acquisition de ces chiens d'assistance s'est fait par le biais d'écoles pouvant émettre un certificat d'accès public (Wilderwood service dogs aux EU et MSAR service dogs au Canada).

Société Alzheimer Society

CANADA



RECOMMANDATIONS

1. Promouvoir l'éducation du public et des professionnels de la santé sur les chiens d'assistance neurologique et les avantages potentiels des chiens de compagnie (en termes de but/sens de la vie et de relation positive)
2. Accroître l'accessibilité des chiens de compagnie dans certaines installations publiques
3. Accroître l'accessibilité aux écoles de dressage de chiens et aux programmes de financement connexes
4. Évaluer cliniquement si la personne est capable de s'occuper seule du chien d'assistance neurologique si nécessaire, à la fois en termes de mobilité et de cognition.
5. Le dressage des chiens neurologiques devrait s'assurer que le chien ne présente pas de risque de chute et peut même aider à cet égard.

Valeur ajoutée du neuro chien d'assistance par rapport à un chien de compagnie

Le neuro chien d'assistance

Accompagne pour faire de l'activité physique (ex. aller au gym)

Agit comme un agent de socialisation dans les endroits publics (ex. commerce, aéroport, clinique, église, restaurant)

Aide à mieux dormir

Contribue au sens et au but de la vie

Aide à guider la personne en toute sécurité dans son environnement

Tâches spécifiques

Fournit du réconfort et de la compagnie lorsque la personne est anxieuse, sort dehors et la nuit

Aide à rappeler à la personne les routines et les tâches quotidiennes

Guide en toute sécurité la personne vers un espace désigné si elle devient désorientée en public

Rappelle à la personne la tâche à accomplir si elle est désorientée

Bienfaits potentiels :

- Accès dans les endroits publics intérieurs et extérieurs
- Liberté pour l'aidant de sortir ou de garder un travail à l'extérieur
- Focus positif sur le chien (parle du chien aux gens lors des interactions, prend soin de son chien, etc.)
- Bien-être et qualité de vie
- Meilleure routine
- Réduction du stress
- Surveillance du sommeil

Considérations:

- Coût d'acquisition >15 000\$
- Temps requis pour l'acquisition et la formation
- Réactions négatives d'employés et de clients à l'occasion
- Deuil suite au décès du chien ou d'une séparation avec celui-ci lors du déplacement vers un hébergement de soins longues durées
- Focalisation inappropriée sur le chien (ex. anxiété à propos de la santé du chien)

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#ID : _____

Date : _____

Guide d’entrevue individuelle administré par téléphone

(Aidant)

Les chiens de soutien à la démence : leur impact sur la vie des personnes présentant une démence légère à modérée et leur aidant vivant dans la communauté.

INTRODUCTION

Bienvenue à cette entrevue téléphonique, je vous remercie d’avoir accepté d’y participer.

Présentation de l’animateur

Je me présente, Frédéric Dumont, je suis le coordonnateur de recherche pour le projet « Les chiens de soutien à la démence : leur impact sur la vie des personnes présentant une démence légère à modérée et leur aidant vivant dans la communauté ».

But de la rencontre

À partir de votre position particulière d’aidant qui possède un chien ou qui en désire un¹, et en considérant votre expérience des dernières années, j’aimerais connaître votre perception en ce qui a trait à l’utilisation de votre chien.

Déroulement de la rencontre :

Lecture du formulaire d’information et de consentement oral (5 à 10 minutes) *déjà fait

Durée : 30 à 45 minutes pour l’entrevue, 5 minutes pour la partie sociodémographique.

Par la suite (ou à un autre moment), j’aimerais m’entretenir quelques minutes avec votre proche pour qu’il nous parle de son chien

Entrevue comporte

4 grandes questions ouvertes:

Le rôle du chien avec votre proche _____ (ex. son engagement, socialisation, sécurité, rassurant, activité physique, dormir).

Les obstacles/problèmes rencontrés pour le proche _____ avec son chien (ex. accessibilité avec le chien dans la communauté, socialisation, les pauses requises pour le chien, autres soins pour le chien) ;

Les avantages et les inconvénients pour l’aidant avec l’utilisation du chien (sécurité, indépendance, impact économique);

Votre opinion quant à encourager le recours à l’assistance canine pour les autres aidants et leur proche atteint de démence.

2 séries de questions à choix de réponse (standardisées) :

¹ Toutes les parties en **jaune** ne doivent pas être demandées si l’aidant n’a pas de chien.

information sur le proche
mesure des difficultés ressenties par l'aidant

Il y a une limite de temps pour chaque question, afin de couvrir l'ensemble des questions dans le temps prévu.

Il n'y a pas de bonnes ou de mauvaises réponses, je veux simplement recueillir votre point de vue.

Garder en tête que je suis intéressé autant par les commentaires positifs que négatifs.

Je vous rappelle que la séance est enregistrée sur bande audio, ce qui me permet de me concentrer sur l'entretien et de ne pas avoir à prendre de notes pendant que vous me parlez.

Je vous assure une confidentialité absolue.

Avez-vous des questions avant de débiter l'entretien ?

Heure (début) : _____

QUESTIONS OUVERTES (Partie 1)

Question 1 (professionnel de recherche) :

Comment décririez-vous l'utilisation actuelle du chien pour votre proche?

Faire parler à l'aide de ces points :

motifs d'utilisation (routines et notifications, tâches, activités, contextes)

engagement envers le chien

socialisation

bien-être

activité physique

errance (orientation)

sens à la vie et raison d'exister

qualité de vie, stress, santé

sommeil – le vôtre et celui de votre proche?

Question 2 (Professionnel de recherche) :

Pouvez-vous nommer des obstacles ou problèmes rencontrés lorsque votre proche se promène avec le chien dans la communauté?

Faire parler à l'aide de ces points :

comportement ou réaction des employés des différents commerces/services visités

réaction de la famille ou des proches aidants

santé et comportement du chien

réaction des gens dans la rue

accès à des endroits pour que le chien fasse ses besoins

Question 3 (Professionnel de recherche) :

En tant qu'aidant, quels sont/seraient les avantages et les inconvénients d'avoir un chien dans la maison avec vous ?

Faire parler à l'aide de ces points :

prise de médication

entretien du chien (soins, alimentation, vétérinaire, etc.)

sentiment de sécurité en général

le chien surveille le sommeil et les siestes du proche

indépendance,

engagement

qualité de vie

impact économique (garder son travail?)

coûts liés à l'acquisition et au dressage

gérer la possibilité qu'un jour le proche pourrait être mieux en résidence (y amener le chien, garder le chien)

offrir au chien des pauses de son travail (voir si l'aidant structure consciemment ces moments (moment, durée))

Question 4 (professionnel de recherche) :

Quelle est votre opinion quant à la recommandation d'un chien dans l'avenir pour les aidants et leurs proches avec la démence? Est-ce que l'assistance canine devrait être encouragée et pourquoi ?

QUESTIONS CHOIX DE RÉPONSE (Partie 2)

Maintenant, pour la 2^{ième} partie de l'entrevue, je vais vous poser une série de questions standardisées, avec choix de réponse (oui/non, jamais à très souvent) au sujet de la routine de votre proche, puis du rôle d'aidant en général et de ce que cela implique pour vous.

Mesure du degré de difficultés ressenties par l'aidant

INFORMATION GENERALE

Genre: H F

Quelle est votre relation avec la personne atteinte (conjoint, parent, frère, sœur, ami, etc.):

Nombre d'année d'étude: _____

INFORMATION À FOURNIR SUR LA PERSONNE ATTEINTE

Veuillez indiquer laquelle des descriptions suivantes correspond le mieux à la situation de la personne à qui vous offrez des soins:

	Oui	Non
Il / elle peut sortir et faire des courses seul	<input type="checkbox"/>	<input type="checkbox"/>
2. Il/elle peut gérer les activités quotidiennes sans aide (se laver, s'habiller, etc..)	<input type="checkbox"/>	<input type="checkbox"/>
3. Il / elle a besoin d'aide pour se déplacer à l'intérieur à la maison.	<input type="checkbox"/>	<input type="checkbox"/>
4. Il / elle passe plus de la moitié de la journée au lit ou assis	<input type="checkbox"/>	<input type="checkbox"/>
5. Il / elle est pratiquement totalement confiné au lit ou à une chaise.	<input type="checkbox"/>	<input type="checkbox"/>

MESURE DU DEGRÉ DE DIFFICULTÉS RESENTIES PAR L' Aidant (MDDRA)⁴

Nous aimerions connaître votre expérience d'aidant auprès d'un malade. Dans ce qui suit, vous trouverez une liste d'énoncés pouvant faire partie de l'expérience d'accompagnants. Ainsi, pour chaque énoncé, veuillez encercler le chiffre qui représente le mieux, de "jamais" à "très souvent", votre situation ces jours-ci.

EXEMPLE :		Jamais	De temps en temps	Assez souvent	Très souvent
1.	Vous arrive-t-il d'avoir de la difficulté à vous concentrer ?	1	2	3	4

Cet exemple indiquerait que vous considérez que, très souvent, vous avez de la difficulté à vous concentrer.

Ne prenez pas trop de temps pour répondre : votre première impression est probablement la meilleure.

Ces jours-ci ...	Quelle est la fréquence à laquelle votre rôle d'aidant vous amène à ressentir cette expérience			
	Jamais	De temps en temps	Assez souvent	Très souvent
1. Vous arrive-t-il de trouver que les tâches reliées aux soins du malade sont trop exigeantes ?	1	2	3	4
2. Vous arrive-t-il de vous sentir émotivement épuisé(e) ?	1	2	3	4
3. Vous arrive-t-il de sentir que vous n'avez plus la force de prendre soin de la personne malade ?	1	2	3	4
4. Vous arrive-t-il de vous sentir à bout de souffle ?	1	2	3	4
5. Vous sentez-vous dépassé(e) par tout ce qui vous arrive ?	1	2	3	4
6. Vous sentez-vous à la hauteur de la situation ?	1	2	3	4
7. Avez-vous l'impression que votre rôle de soignant vous rend physiquement malade ?	1	2	3	4
8. Vous arrive-t-il de vous sentir émotivement vidé(e) ?	1	2	3	4
9. Vous arrive-t-il d'avoir l'impression de ne plus être capable de prendre soin de la personne malade ?	1	2	3	4
10. Vous arrive-t-il de vous sentir physiquement épuisé(e) ?	1	2	3	4

	Jamais	De temps en temps	Assez souvent	Très souvent
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11.	Avez-vous l'impression d'être en contrôle de la situation ?	1	2	3	4
12.	Vous arrive-t-il d'avoir peur de ne plus pouvoir tenir le coup bien longtemps ?	1	2	3	4
13.	Vous sentez-vous au bout de votre rouleau ?	1	2	3	4
14.	Êtes-vous mal à l'aise dans les soins que vous avez à donner à la personne malade ?	1	2	3	4
15.	Vous arrive-t-il d'être découragé(e) par toutes les tâches que vous avez à faire ?	1	2	3	4
16.	Vous arrive-t-il de penser que l'accompagnement est une expérience trop exigeante pour vous ?	1	2	3	4
17.	Vous arrive-t-il d'avoir l'impression de perdre le contrôle sur votre vie ?	1	2	3	4
18.	Vous arrive-t-il d'avoir l'impression de porter un trop grand poids sur les épaules ?	1	2	3	4

CONCLUSION :

Y aurait-il des points dont nous n'avons pas discutés et que vous aimeriez ajouter ?

Avant peut-être de rencontrer votre proche pour qu'il nous parle de son chien, nous devons compléter les informations sur les données sociodémographiques et professionnelles vous concernant.

VARIABLES SOCIODÉMOGRAPHIQUES ET PROFESSIONNELLES (partie 3):

Genre : F H autre

Province : TN NB NE IPE QC ON MA SA AL BC

Votre âge en années (pour pouvoir produire des statistiques précises) : _____

Nombre d'années depuis que votre proche a reçu un diagnostic de démence ? : _____

Est-ce que d'autre personne habite sous le même toit que vous et votre proche non. oui

Si oui, précisez qui (parent, conjoint, enfant, ami, autre parenté, autre:

Habitez-vous en campagne, banlieue, ville sur une ferme

Dans quel type d'habitation résidez-vous?

Maison (propriétaire), précisez type :

Bungalow, cottage, jumelé, maison en rangée/maison de ville, _____

Condo (propriétaire) précisez nombre de pièces : _____

Appartement ou condo (locataire) précisez nombre de pièces : _____

Occupation principale actuellement (cochez un ou plusieurs choix):

retraîtée

aidant naturel

études

travail

bénévolat

rôle familial (s'occupe des enfants ou des parents)

autre _____

Quel âge à votre chien : _____

S'agit-il d'un 1^{er} chien ou non ? Sinon, d'un 2^{ième} ? 3^{ième} ? _____

Nombre d'années depuis l'obtention de votre chien : _____.

Où avez-vous obtenu votre chien : animalerie don d'une connaissance via une école de chien
refuge SPCA éleveur autre _____

Race : _____

Taille du chien : petite moyenne grande

Lieu de l'entraînement du chien (s'il y a lieu) : _____

Durée de l'entraînement du chien (s'il y a lieu) : _____

Type de déplacements effectués avec le chien (cocher si oui)

Déplacements intérieurs dans des commerces (resto, magasins, centres d'achat, salles de spectacle, cinémas, arénas...)

Déplacements intérieurs pour l'obtention de services (santé, finances, école...)

Déplacements extérieurs à pieds sur le réseau routier et piétonnier

Déplacement extérieurs à pieds dans les parcs, plages, sentiers pédestres, etc.

Voyager en auto

Voyager en autobus

Voyager en train

Voyager en avion

Autres types de déplacements: _____

Y a-t-il d'autre animal vivant dans votre résidence en plus de votre chien? Non Oui.

Si oui, lesquels, combien? _____

Merci beaucoup d'avoir accepté de me parler, vos commentaires me sont très précieux et très utiles. J'espère que vous avez apprécié l'expérience.

Heure (fin) : _____

Pour vous faire parvenir le 50\$ de frais de compensation, pourriez-vous nous donner votre adresse?

NB L'adresse ne sera pas rapportée dans la base de données

MINI-ENTREVUE AVEC LE PROCHE (Partie 4)

non, pas de consentement de la part du proche

Si votre proche accepte, pour 2 à 3 minutes seulement,

Il pourra être audio-enregistré au téléphone immédiatement.

Voici les deux questions pour le proche :

Comment le chien travaille-t-il pour vous du matin au soir ? et la nuit?

Comment le chien vous aide-t-il?

#ID: _____

Date: _____

Individual interview guide administered by phone

(Caregiver)

Dementia dogs: Their impact on community-dwelling persons with mild to moderate dementia and their caregiver.

INTRODUCTION

Welcome to this telephone interview, thank you for your participation.

I am Frédéric Dumont, the research coordinator for the project entitled « Dementia dogs: Their impact on community-dwelling persons with mild to moderate dementia and their caregiver ».

Purpose of this interview

From your particular position of caregiver who has a dog or wishes to acquire one², and considering your experience of the last year, I would like to know your perception of the use of a dog.

Sequence of this interview

Reading of the information of verbal consent form (5 to 10 minutes) * done

Duration: 30-45 minutes for the interview, 5 minutes for the demographic questionnaire.

Afterwards, or another time, I would like to talk for a few minutes to the person you care for, to talk about his dog

Interview includes:

4 open questions:

The role of the dog with your beloved³ _____ (e.g. engagement, socialization, safety, calming, physical activity, sleeping);

Obstacles/problems with the dog and the beloved³ _____ (e.g. approachability situations, socialization experiences, dog's need for break time, extra care needs of dog)

Advantages and disadvantages for the caregiver with a dog in the house (security, independence, economic issues);

Your opinion about recommending canine assistance for other caregivers and the person to whom they provide care

2 series of response options questions (standardised):

about the person to whom you provide care

measurement of the difficulty of caregiving

There is a time limit for each question, in order to cover all issues in the allocated time.

There are no right or wrong answers; I just want to know your point of view.

² All text in **yellow** should not be requested if the caregiver doesn't have a dog.

³ Beloved or loved one should be replaced by the exact relationship mentioned in General information (partner, spouse, parent, brother, sister, friend, etc.):

I would remind you that this interview is recorded, which allows me to concentrate on the interview and not having to take notes while you speak to me.

Keep in mind that I am as much interested to know your positive comments as well as your negative ones.

I assure you a strict confidentiality.

Do you have questions before the beginning of the interview?

Time (starting) : _____

OPEN QUESTIONS (part 1)

Question 1 (research professional):

How would you describe the actual use of the dog by the person to whom you provide care?

Hints:

usage patterns (routines and notifications, tasks, activities, contexts)

engagement towards the dog

socialization

well-being

physical activity

wandering (orientation)

meaning and purpose

quality of life, stress, health

sleep – both yours and your loved one's

Question 2 (research professional)

What barriers/issues have affected the person to whom you provide care when out in the community with the dog?

Hints:

behavior or reaction of employees of different shops/services

reaction of family or caregivers

health and behavior of the service dog

reaction of people in the street

availability of dog toileting sites

Question 3 (research professional):

As a caregiver, what are the advantages and disadvantages of having a dog in the house with you?

Hints:

taking medication

maintenance of the dog (care, feeding, veterinary, etc.)

general feeling of security

dog monitors loved one's sleep and napping

independence

engagement

quality of life

economic impact (keep employment)
 costs related to dog acquisition and training
 dealing with possible placement of the beloved³ _____ in residential care (bring the dog, keep the dog)
 providing the dog breaks from working (try to identify if the caregiver consciously structures in time, duration)

Question 4 (research professional)

What is your opinion regarding the future of canine assistance for caregivers and persons with dementia to whom they provide care? Should this be encouraged and why or why not?

QUESTIONS WITH RESPONSE OPTIONS (Part 2)

Now, for the 2nd part of the interview, I'll ask you a series of standardized questions, with responses options (yes/no, never to very often), about the routine of your loved one³ _____, then the role of caregiver in general and what this means for you.

Caregiver's Burden Scale

GENERAL INFORMATION

Gender: male female

What is your relationship to the ill person (partner, spouse, parent, brother, sister, friend, etc.):

Number of years of schooling: _____

INFORMATION ABOUT THE PERSON TO WHOM YOU PROVIDE CARE

Please indicate which of the following descriptions most closely reflects the situation of the person to whom you provide care:

	Yes	No
He/ she can go out and run errands alone and without assistance	<input type="checkbox"/>	<input type="checkbox"/>
He/ she can manage daily activities without help (washing, eating, dressing, etc.)	<input type="checkbox"/>	<input type="checkbox"/>
He/ she requires assistance to move around inside at home.	<input type="checkbox"/>	<input type="checkbox"/>
He/ she spends more than half of the day in bed or in a chair.	<input type="checkbox"/>	<input type="checkbox"/>
5. He/ she is practically completely confined to bed or chair.	<input type="checkbox"/>	<input type="checkbox"/>

Caregiver's Burden Scale

We would like to know about your experience while caring for an ill person. In the following document, you will find a list of statements that may or may not be part of a caregiver's experience. For each item, please **circle the number** (from "never" to "very often") that best describes your current situation.

EXAMPLE :		Never	From time to time	Fairly often	Very often
1.	Do you have trouble concentrating?	1	2	3	4

This example indicates that you consider that, very often, you have trouble concentrating.

Don't take too much time responding; your first impression is probably the best.

		How often do you experience this feeling in your role as caregiver?			
Currently		Never	From time to time	Fairly often	Very often
1.	Do you ever find that the tasks required in caring for the sick person are too demanding?	1	2	3	4
2.	Do you ever feel emotionally exhausted?	1	2	3	4
3.	Do you ever feel that you no longer have the strength to care for the ill person?	1	2	3	4
4.	Do you ever feel unable to go on?	1	2	3	4
5.	Do you feel overwhelmed by everything that has happened to you?	1	2	3	4
6.	Do you feel that you are up to dealing with this situation?	1	2	3	4

How often do you experience this feeling in your role as caregiver?

	Currently	Never	From time to time	Fairly often	Very often
7.	Do you have the impression that your role as caregiver is making you physically ill?	1	2	3	4
8.	Do you ever feel emotionally drained?	1	2	3	4
9.	Do you ever feel that you are no longer capable of caring for the ill person?	1	2	3	4
10.	Do you ever feel physically exhausted?	1	2	3	4
11.	Do you have the impression that you are in control of the situation?	1	2	3	4
12.	Are you ever afraid that you won't be able to hold out much longer?	1	2	3	4
13.	Do you feel like you are at the end of your rope?	1	2	3	4
14.	Are you uncomfortable with the type of care you must provide the ill person with?	1	2	3	4
15.	Do you ever feel discouraged by all the tasks you have to accomplish?	1	2	3	4
16.	Do you ever think that caregiving is too demanding an experience for you?	1	2	3	4
17.	Do you ever have the impression that you have lost control over your life?	1	2	3	4
18.	Do you ever have the impression that you carry too heavy a burden?	1	2	3	4

© Dumont & al., 1999

CONCLUSION :

Are there points which we have not discussed and that you would like to add?

Before possibly speaking to your loved one³ _____ to talk about his/her dog, we must complete the demographic and occupational information about you.

DEMOGRAPHIC AND PROFESSIONAL VARIABLES (part 3) :

Province : NF NB NS PEI QC ON MA SA AL BC

Sex : F M other

Age in years (to provide the most precise statistics)

Number of years since your beloved³ _____ was diagnosed with dementia : _____

Does anyone else live under the same roof as you and your loved one³ ____ No Yes

If yes, specify (parent, spouse, child, friend, other relatives. other:

Do you live in rural area, suburban, city on a farm

What type of home do you live in?

House (owner), please specify :

Bungalow, semi-detached, townhouse, other _____

Condo (owner), number of bedrooms : _____

Apartment or condo (tenant), number of room : _____

Main occupation:

Retired

Caregiver

Study

Work

Volunteerism

Family role (care for children or parents)

Other _____

How old is your dog : _____

Is it your 1st dog? Yes No 2nd 3rd _____

Number of years since the acquisition of your current dog: _____

This dog came from: pet shop a donation from an acquaintance dog training school dog shelter Canadian Society Animal Protection breeder other _____

Breed: _____

Dog's size : small medium large or tall

Place where the dog has been trained (if there is one) : _____

Duration of your dog's training (if there is one) : _____

Type of travel with the service dog (choose all that apply):

Moving inside commercial buildings (restaurant, stores, banks, cinemas, arenas, sport clubs...)

Moving in service areas (health, financial, schools...)

Moving outside on foot on the street or pedestrian area

Moving outside on foot in parks, on beaches, hiking trails, etc.

traveling by car

traveling by bus

traveling by train

traveling by airplane

Other types of travel: _____

Other animal in your house in addition to your current dog? No Yes.

If yes, what is it? : _____

Thank you very much for accepting to talk to me, your comments are very valuable and very useful. I hope you enjoyed the experience.

Hour (end) : _____

To send you the 50\$ of compensation, would you please give me your address?

NB The address won't be put in the database

MINI-INTERVIEW WITH THE PERSON TO WHOM YOU PROVIDE CARE (Part 4)

No consent from the person with dementia

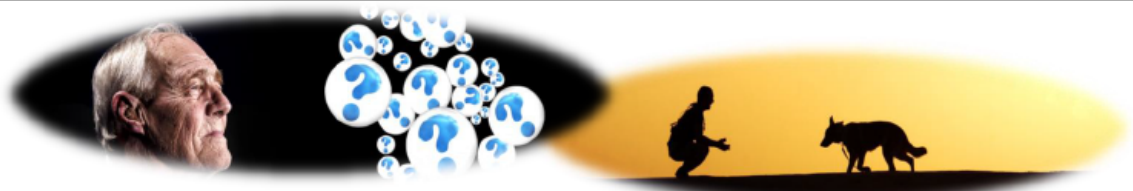
If your beloved³ _____ accepts, for 2 à 3 minutes only,

we can audio-recorded him right now on phone

Here are the two questions for the beloved³ _____:

How the dog works with you for you during the day starting from when you get up until bedtime? At night?

How does your dog help you?



Dogs and people with dementia

Dementia dogs and their impact on persons dwelling in the community with mild to moderate dementia and their caregiver

Research Project Volunteer Participants

To learn about and document from your experiences with the added value of companion dogs and service dogs from the perspective of persons with mild to moderate dementia and their caregiver.

The participants (persons with mild to moderate dementia and their caregiver living together) should fall into one of these 3 categories.

1. living with a companion dog (pet) for at least one year.
2. living with a service dog for at least one year.
3. who have made the decision not to have a dog.

The research project involves a 45 min. interview phone call and online questionnaires (15 min.) for the caregiver. For the person with dementia there will be an interview call and an activity monitoring wristwatch to be worn for one week.

→ In appreciation for volunteering, persons with dementia and caregivers will receive \$25.00 each.



Contact info - Research coordinator: frederic.dumont@cirris.ulaval.ca

or 418 529-9141 ext. 6033.

Principal investigator: Claude Vincent claud.vincent@rea.ulaval.ca, 418-656-2131 ext. 6078

Contact co-researcher : Dr Suzette suzette.bremault-phillips@ualberta.ca, 780-492-9503

This project has been approved by Université Laval's Research Ethics Board :
Approbation number 2018-185 / 26-10-2018



Des chiens pour les personnes vivant avec des atteintes cognitives (ex. pertes de mémoire)

Les chiens de soutien : leur impact sur la vie des personnes vivant avec des atteintes cognitives légères à modérées et leur aidant vivant ensemble à domicile.

Participants au projet de recherche

La présente étude vise à documenter la valeur ajoutée des chiens de compagnie et des chiens certifiés en tant que soutien aux soins à domicile selon le point de vue des personnes vivant avec des atteintes cognitives et leur aidant.

Nous cherchons à recruter des dyades vivant sous le même toit (personne vivant avec des atteintes cognitives et leur aidant) dans une des trois situations suivantes:

- 1. vivre avec un chien (animal de compagnie) depuis un an ou plus**
- 2. vivre avec un chien d'assistance depuis un an ou plus**
- 3. qui ont pris la décision de ne pas avoir de chien**

La participation consiste pour l'aidant en une entrevue (45 min.) et des questionnaires en ligne (15 min.). Pour la personne vivant avec des atteintes cognitives, il y aura un entretien téléphonique optionnel (5 min.) et une moniteur d'activité physique à porter pendant une semaine.

→ En guise de remerciement, les personnes vivant avec des atteintes cognitives et les aidants recevront 25\$ chacun.



Contact info - Research coordinator: Frédéric Dumont frederic.dumont@cirris.ulaval.ca
or 418 529-9141 ext. 6033.

Principal investigator: Claude Vincent claud.vincent@rea.ulaval.ca, 418-656-2131 ext. 6078. **Contact co-researcher :** Dr Suzette suzette.bremault-phillips@ualberta.ca, 780-492-9503

Ce projet a été approuvé par le Comité d'éthique de la recherche de l'Université Laval :
N° d'approbation 2018-185 A-2 R-1/ 17-10-2019

Information and verbal consent form

Caregivers

Research project

Dementia dogs: Their impact on community-dwelling persons with mild to moderate dementia and their caregiver

Research presentation

This pilot study is funded by Alzheimer Society of Canada and is directed by Dr. Claude Vincent, occupational therapist (OT), professor at the Rehabilitation Department of *Université Laval* and researcher at the Center for Interdisciplinary Research in Rehabilitation and Social Integration (CIRRS). claud.vincent@rea.ulaval.ca

Co-researchers

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Suzette Brémault-Phillips, PhD., OT, Professor, Occupational Therapy Department, University of Alberta suzette.bremault-phillips@ualberta.ca

Cary Brown, PhD, OT, Professor, Occupational Therapy Department, University of Alberta. cary.brown@ualberta.ca

Research coordinator: Frédéric Dumont, PhD., CIRRS. frederic.dumont@cirris.ulaval.ca

This document explains the purpose of this research project, procedures, benefits, risks and disadvantages. We invite you to ask any questions you have to the persons identified at the end of this document. Before agreeing to participate in this research project, please take the time to read and understand the following information. Please let us know after reading the document if you need more time to decide if you want to participate.

Nature of the study

This research project aims to examine how canine assistance may support family caregivers living with persons with a mild to moderate dementia.

To be **included** in the study you need to:

1. be the caregiver of a person with mild to moderate dementia and living in the same home.
2. have a companion dog OR to have a certified emotional support dog, OR not having a dog but willing to acquire one.

What are we asking you to do?

The study consists of one phone interview, three on line questionnaires, a video or audio-record of your loved one with the dog and your loved one wearing an activity monitor (looks like a wrist watch) for 7 days and nights.

1. Specifically, we will begin with a telephone interview (about 30-45 minutes) about your experience of caregiving and of the impact (or not) of the dog in the life of your loved one. Interview will be shortened if you do not have a dog.
2. If your loved one agrees, we would like to hear him/her on the phone talking about the effect of their dog.
3. Following the interview, we will ask you to complete three questionnaires online (about 15 minutes). One relates to your quality of life, the other to your daily tasks and your role as caregiver and the last one concerns time spent in daily tasks. This will allow us to explore cost-effectiveness associated with canine support at home for the people with dementia in the study.
4. If you and your loved one agree to participate, you will receive an activity monitor (looks like a wristwatch) for your loved one to wear on their non-dominant wrist for 7 consecutive days (except when he/she is bathing). This will allow us to collect information about his/her level of activity around the house and their quality of sleep. Then, in a prepaid envelope, you will return the activity monitor to us. If your relative does not want to wear an activity monitor you can still participate in the study for the interview and questionnaires.

Benefits, risks and possible downsides associated with your participation

Taking part in this research offers you the opportunity to help determine the impact of canine assistance for caregivers of people with a dementia living at home.

It is possible that answering the questions may raise unpleasant memories, emotions and thoughts. If this occurs, you can stop answering questions with no penalty. Please discuss any unpleasant affects you may have with the interviewer. The interviewer will give you the contact details for resources able to assist you if needed (ex. [local Alzheimer Society](#)).

Compensation

We provide a \$25 reimbursement after the interview to compensate you for the time/costs incurred by participating in this research project.

Voluntary participation and right of withdrawal

Your participation is completely voluntary. You are free to end your participation without negative consequences or prejudice and without having to justify your decision. You can withdraw from the study and ask to have your data removed up until 2 weeks after all data have been collected. After that time the data will be anonymized and, because we cannot identify it as belonging to you, we will no longer be able to remove your data.

Privacy and Data Management

The following measures will be implemented to ensure the confidentiality of information provided by the participants:

- neither you, nor any other participants, will be named in any reports;
- individuals in the study will be given a code and we will only refer to your data by code. Only the research team will be able to match the participants' codes to their names;
- the individual results of the participants will never be disclosed;
- data and archives will be stored securely (in a password protected, encrypted computer in a locked office) and will be destroyed five years after the end of the project, i.e. in 2025.
- this research will be the subject of publications in scientific journals and presentations but no participant will be identified;
- a short summary of research results will be sent to participants upon request

Despite the measures taken to ensure the confidentiality, integrity, and security of data transmitted online, using the Internet involves certain risks of intrusion by third parties, manipulation and loss of data or identification.

For your protection, the Ministry of Health and Social Services of the Province of Quebec asking all ethics committees to require that the researcher keeps, for at least one year after the end of the project, the list of research participants with their coordinates, so that, if necessary, they can be contacted quickly.

Incapacity mandate

If the person with mild or moderate dementia is the subject of an incapacity mandate and that you are the representative, you can consent to his/her participation after reading his/her information form.

Statement of verbal consent (this will be audio-recorded)

- Do you understand the project and the implications of your participation?
- Do you want more time to think about your participation? If so, tell us the best time to contact you. Otherwise,
- Do you agree to confirm, on this recording, that you consent to participate in this study?

Acknowledgments

Your cooperation is valuable to understanding the role of dementia dogs and we thank you for your participation.

Additional information

If you have questions about this project, your participation or if you wish to interrupt your participation, please contact Dr. Claude Vincent (head researcher), at the following telephone number: 418 529-9141 ext 6626, or to the following email address claud.vincent@rea.ulaval.ca

Complaints or critics

Any complaints or critics about this research project may be addressed to the Ombudsman's Office of Laval University:
Pavillon Alphonse-Desjardins, bureau 3320
2325, rue de l'Université
Université Laval
Québec (Québec) G1V 0A6
Renseignements - Secrétariat : (418) 656-3081
Ligne sans frais : 1-866-323-2271
Courriel : info@ombudsman.ulaval.ca

INFORMATION AND VERBAL CONSENT FORM

Participant who has a mild to moderate dementia

RESEARCH TITLE: Dementia dogs: Their impact on community-dwelling persons with mild to moderate dementia and their caregiver.

PRINCIPAL RESEARCHER : Claude Vincent, PhD., occupational therapist (OT), from the Rehabilitation Department of *Université Laval* and Center for Interdisciplinary Research in Rehabilitation and Social Integration (CIRRS). claud.vincent@rea.ulaval.ca

CO-RESEARCHERS: Bertrand Achou, PhD., economist, Professor, Département des sciences économiques, Université Laval. bertrand.achou@cirris.ulaval.ca
Suzette Brémont-Phillips, PhD., OT, Associate Professor, Occupational Therapy Department, University of Alberta suzette.bremault-phillips@ualberta.ca
Cary Brown, PhD, OT, Professor, Occupational Therapy Department, University of Alberta. cary.brown@ualberta.ca

RESEARCH COORDINATOR: Frédéric Dumont, PhD., Center for Interdisciplinary Research in Rehabilitation and Social Integration (CIRRS). *Université Laval*. frederic.dumont@cirris.ulaval.ca

NATURE OF THE STUDY

Our research project was funded by the Alzheimer Society of Canada to study the impact of canine assistance in the home of caregivers living with people with mild to moderate dementia. Results of this research will possibly provide new home care solutions for caregivers and their families living with dementia, i.e. non-pharmacological and non-conventional health care solutions.

WHAT WILL WE ASK YOU TO DO?

1. We will ask you to explain in your own words « **What are the things your dog does for you during the day from getting up until bedtime?** », and « **do you enjoy having your dog near you at all times? Why?** ».
2. In one week, you will receive an activity monitor (this looks like a wristwatch) that your caregiver will ask you to wear on your wrist for 7 consecutive days (except for showering or bathing). This will allow us to measure your physical activity and watch the quality of your sleep. You have nothing to do, just wear the watch. Your caregiver will return it to us by mail in a prepaid envelope thereafter.



CONFIDENTIALITY

Researchers are required to ensure confidentiality to participants. In this regard, the following measures will be applied in this research:

During the research:

- your name will be replaced by a code in all material and research data containing personal information;

- only the researcher will have access to the list containing the names and codes, which is kept separately from the research material and data;
- all the research material will be kept in a locked file in a locked room;
- data in digital format will be stored in encrypted files whose access will be protected by the use of a password and to which only the researcher will have access;

When disseminating the results:

- the names of the participants will not appear in any report;
- the results will be presented in aggregate form so that the individual results of the participants will never be communicated;
- the results of the research will be published in scientific journals, and no participant can be identified;
- a short summary of the research results will be sent to participants who request it to the researcher whose contact information is provided in this document.

After the end of the search:

- the list of names and codes will be destroyed so that the data that will be used in other research is anonymized without any absolute possibility of identifying the participants who provided it.

CAN I WITHDRAW FROM THE STUDY?

You can withdraw from the study and ask to have your data removed up until 2 weeks after all data has been collected. After that time the data will be anonymized and, because we cannot identify it as belonging to you, we will no longer be able to remove your data.

Compensation

We provide a \$25 reimbursement after the interview to compensate you for the time/costs incurred by participating in this research project.

Incapacity mandate

If the person with mild or moderate dementia is the subject of an incapacity mandate and that you are the representative, you may consent for her/his participation by answering the following questions (audio-recorded):

- Do you understand the project and the implications for the person you represent?
- Do you want more time to think about it? If so, tell us the best time to contact you. Otherwise,
- Do you agree to confirm, on this recording, that you give your consent for the person you represent to participate in this study?

Verbal certificate of consent for the person with dementia (if no incapacity mandate)

Will be audio-recorded

- Do you understand the project and the implications of your participation?



7 days and nights + record 2-3 minutes on



- Do you want more time to think about your participation? If so, tell us the best time to contact you again. If not,
- Do you agree to confirm on this audio recording that you agree to participate?

Acknowledgements

Your collaboration is precious for us to carry out this study and we thank you for your participation.

ADDITIONAL INFORMATION

If you have questions about this project, your participation or if you wish to interrupt your participation, please contact Dr. Claude Vincent (head researcher), Université Laval at the following telephone number: 418 529-9141 ext. 6626, or to the following email address claud.vincent@rea.ulaval.ca.

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Information - Secrétariat : (418) 656-3081
Free call : 1-866-323-2271
Courriel : info@ombudsman.ulaval.ca

FEUILLET D'INFORMATION POUR UN CONSENTEMENT VERBAL

Aidant

Titre du projet de recherche

Les chiens de soutien à la démence : leur impact sur la vie des personnes présentant une démence légère à modérée et leur aidant vivant à domicile dans la communauté.

Présentation de la recherche

Cette étude est financée par la Société Alzheimer et dirigée par la **Dre Claude Vincent**, ergothérapeute (OT) et professeure au département de réadaptation de l'Université Laval et chercheure au Centre interdisciplinaire de recherche en réadaptation et intégration sociale (CIRRS)

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Coordonateur de recherche: Frédéric Dumont, PhD., CIRRS. frederic.dumont@cirris.ulaval.ca

Ce document vous explique le but de ce projet de recherche, ses procédures, avantages, risques et inconvénients. Nous vous invitons à poser toutes les questions que vous jugerez utiles à la personne identifiée à la fin de ce document. Avant d'accepter de participer à ce projet de recherche, veuillez prendre le temps de lire et de comprendre les renseignements qui suivent. À la fin de la lecture, il vous sera proposé plus de temps pour pouvoir prendre votre décision.

Nature de l'étude

Ce projet de recherche a pour but d'étudier l'impact de l'assistance canine au domicile des proches aidants vivant avec des personnes qui présentent une démence légère à modérée.

Les critères **d'inclusion** sont:

1. Être le proche aidant d'une personne présentant une démence légère à modérée et vivant sous le même toit.
2. Posséder un chien de compagnie, OU un chien certifié de soutien pour la démence, OU ne pas avoir de chien mais souhaiter en avoir un.

Déroulement de la participation

Les évaluations seront effectuées au moyen d'un guide d'entrevue, de deux questionnaires, du vidéo de votre proche avec son chien, et du port d'une montre par votre proche.

3. Plus précisément, nous débiterons par un **guide d'entrevue téléphonique** d'environ 30-45 minutes sur votre expérience d'aidant et de l'impact (ou non) du chien dans la vie de votre proche au domicile
4. Suivant l'entrevue, nous vous demanderons de compléter deux **questionnaires** en ligne (15 minutes). L'un porte sur votre qualité de vie et l'autre, sur vos tâches quotidiennes incluant celles liées à votre rôle d'aidant. Ceci nous permettra de faire une analyse cout-efficacité associée liée à l'assistance canine au domicile des personnes atteintes de démence. Il est à noter que les questionnaires sont copyright en anglais (tel que nous l'a indiqué le chercheur en économie), et qu'il ne nous est pas légalement possible de les traduire. Si vous ne maîtrisez pas suffisamment l'anglais pour y répondre, seulement nous l'indiquer, et vous pouvez quand même demeurer quand même dans notre étude.
5. Si votre proche accepte, nous aimerions qu'il nous présente par téléphone son chien et qu'il nous indique ce que le chien fait pour lui.
6. Dans une semaine, vous recevrez un moniteur d'activité (**ressemble à une petite montre bracelet**); votre proche devra le porter au poignet pendant 7 jours consécutifs (sauf pour la douche). Ceci nous permettra de caractériser le niveau d'activité physique autour de la maison et la qualité du sommeil de personnes atteintes de démence légère et modérée. Ensuite, dans l'enveloppe préaffranchie acheminée, il faudrait nous retourner la montre. Si votre proche ne veut pas porter un moniteur d'activité, vous pouvez toujours participer à l'étude pour l'entrevue et les questionnaires.⁴

Avantages, risques ou inconvénients possibles liés à votre participation, (compensation, le cas échéant)

Le fait de participer à cette recherche vous offre une occasion de contribuer à démontrer les effets des chiens pour les aidants des personnes atteintes de démence légère à modérée, pour le soutien à domicile.

Il est possible que le fait de raconter votre expérience suscite des réflexions ou des souvenirs émouvants ou désagréables. Si cela se produit, n'hésitez pas à en parler avec la personne qui mène l'entrevue (moi). Je pourrai vous mentionner le nom d'une ressource en mesure de vous aider, au besoin.

Compensation :

Un montant forfaitaire de 25\$ vous sera posté à la suite de l'entrevue, afin de compenser les frais/temps encourus par votre participation à ce projet de recherche.

Participation volontaire et droit de retrait

Vous êtes libre de participer à ce projet de recherche. Vous pouvez aussi mettre fin à votre participation sans conséquence négative ou préjudice et sans avoir à justifier votre décision. Vous pouvez vous retirer de l'étude et demander que vos données supprimées jusqu'à deux semaines après que toutes les données ont été recueillies. Passé ce délai les données vont être anonymisées et nous ne pourrons plus identifier celles comme vous appartenant, donc nous ne serons plus en mesure de supprimer vos données. Si vous décidez de mettre fin à votre participation, il est important d'en prévenir le chercheur dont les coordonnées sont incluses dans ce document. Tous les renseignements personnels vous concernant peuvent être détruits à votre demande.

Confidentialité et gestion des données

Les mesures suivantes seront appliquées pour assurer la confidentialité des renseignements fournis par les participants:

^{4 4} Veuillez noter que le formulaire de consentement implicite pour le participant atteint de démence a été envoyé par courriel à l'aidant au même moment que le présent formulaire de consentement verbal. Une réunion téléphonique est prévue avec l'aidant de consentir verbalement (enregistrement sonore), réaliser l'entretien téléphonique et après cela, d'inviter la personne atteinte de démence à participer (vidéo ou parler au téléphone).

- les noms des participants ne paraîtront dans aucun rapport;
- les divers documents de la recherche seront codifiés et seul le chercheur et un professionnel de recherche aura accès à la liste des noms et des codes;
- les résultats individuels des participants ne seront jamais communiqués;
- les données et les enregistrements, seront conservés de façon sécuritaire (ex : lieu, matériel sous clé ou données sur ordinateur protégé par un mot de passe) et ils seront détruits 5 ans après la fin de la recherche, soit en 2025.
- la recherche fera l'objet de publications dans des revues scientifiques, et aucun participant ne pourra y être identifié ;
- un court résumé des résultats de la recherche sera expédié aux participants qui en feront la demande en indiquant l'adresse où ils aimeraient recevoir le document.

En dépit des mesures prises pour assurer la confidentialité, l'intégrité et la sécurité des données transmises en ligne, l'utilisation d'Internet comporte certains risques d'intrusion par des tiers, de manipulations, de pertes de données et d'identification.

Dans un souci de protection, le ministère de la Santé et des Services sociaux demande à tous les comités d'éthique désignés d'exiger que le chercheur conserve, pendant au moins un an après la fin du projet, la liste des participants de la recherche ainsi que leurs coordonnées, de manière à ce que, en cas de nécessité, ceux-ci puissent être rejoints rapidement.

Mandat d'inaptitude

Si la personne présentant une démence légère ou modérée fait l'objet d'un mandat d'inaptitude et que vous êtes le mandataire, vous pourrez consentir à sa participation après la lecture de son formulaire de d'information.

Attestation verbale du consentement (ceci sera audio-enregistré)

- **Avez-vous bien compris le projet et les implications de votre participation?**
- **Désirez-vous plus de temps pour réfléchir à votre participation ? Si oui, indiquez-nous le meilleur moment pour vous recontacter. Si non,**
- **Acceptez-vous de confirmer, sur cet enregistrement audio, que vous consentez à y participer?**

Remerciements

Votre collaboration est précieuse pour nous permettre de réaliser cette étude et nous vous remercions d'y participer.

Renseignements supplémentaires

Si vous avez des questions sur la recherche, sur les implications de votre participation ou si vous souhaitez vous retirer de la recherche, veuillez communiquer avec Dre Claude Vincent (chercheuse responsable), au numéro de téléphone suivant : 418 529-9141 poste 6626, ou à l'adresse courriel suivante claud.vincent@rea.ulaval.ca .

Plaintes ou critiques

Toute plainte ou critique sur ce projet de recherche pourra être adressée au Bureau de l'Ombudsman de l'Université Laval :

Pavillon Alphonse-Desjardins, bureau 3320
 2325, rue de l'Université
 Université Laval
 Québec (Québec) G1V 0A6
 Renseignements - Secrétariat : (418) 656-3081
 Ligne sans frais : 1-866-323-2271
 Courriel : info@ombudsman.ulaval.ca

FEUILLET D'INFORMATION POUR UN CONSENTEMENT VERBAL

Participant qui présente une démence légère à modérée

Titre du projet de recherche

Les chiens de soutien à la démence : leur impact sur la vie des personnes présentant une démence légère à modérée et leur aidant vivant à domicile dans la communauté

Présentation de la recherche

Cette étude est financée par la Société Alzheimer et dirigée par la **Dre Claude Vincent**, ergothérapeute (OT) et professeure au département de réadaptation de l'Université Laval et chercheure au Centre interdisciplinaire de recherche en réadaptation et intégration sociale (CIRRIIS). claud.vincent@rea.ulaval.ca

Co-chercheurs

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Coordonnateur de recherche

Frédéric Dumont, PhD., CIRRIIS. Ville de Québec. frederic.dumont@cirris.ulaval.ca

RENSEIGNEMENT SUR LE PROJET :

Notre projet de recherche a été financé par la Société Alzheimer du Canada afin d'étudier l'impact de l'assistance canine au domicile des proches aidants vivant avec des personnes qui présentent une démence légère à modérée. Les résultats de cette recherche permettront possiblement de proposer des nouvelles solutions de soutien au domicile des aidants et de leur proche qui vivent avec une démence, i.e. des solutions non pharmacologiques autres que des services de santé classiques.

VOTRE PARTICIPATION :

Nous vous demanderons de nous expliquer dans vos propres mots, « **quelles sont les choses que le chien fait pour vous dans une journée en commençant par le matin jusqu'au soir ?** », et **aimez-vous avoir votre chien près de vous en tout temps? Pourquoi?**».

Dans une semaine, vous recevrez un moniteur d'activité physique (cela ressemble à une montre bracelet) que votre aidant vous demandera de porter au poignet pendant 7 jours consécutifs (sauf pour la douche ou le bain). Ceci nous permettra de mesurer votre activité physique et de regarder la qualité de votre sommeil. Vous n'avez rien à faire, seulement porter la montre. Votre aidant nous la retournera par la poste dans une enveloppe préaffranchie.



CONFIDENTIALITÉ

Les chercheurs sont tenus d'assurer la confidentialité aux participants. À cet égard, voici les mesures qui seront appliquées dans le cadre de la présente recherche :

Durant la recherche:

- votre nom sera remplacé par un code dans tout le matériel et les données de la recherche contenant des renseignements personnels;
- seul le chercheur aura accès à la liste contenant les noms et les codes, elle-même conservée séparément du matériel de la recherche et des données;
- tout le matériel de la recherche sera conservé dans un classeur barré, dans un local sous clé;
- les données en format numérique seront, pour leur part, conservées dans des fichiers encryptées dont l'accès sera protégé par l'utilisation d'un mot de passe et auquel seul le chercheur aura accès;

Lors de la diffusion des résultats :

- les noms des participants ne paraîtront dans aucun rapport;
- les résultats seront présentés sous forme globale de sorte que les résultats individuels des participants ne seront jamais communiqués;
- les résultats de la recherche seront publiés dans des revues scientifiques, et aucun participant ne pourra y être identifié ;
- un court résumé des résultats de la recherche sera expédié aux participants qui en feront la demande au chercheur dont les coordonnées sont fournies dans le présent document.

Après la fin de la recherche :

- la liste des noms et des codes sera détruite afin que les données qui seront utilisées dans le cadre d'autres recherches, soient rendues anonymes sans possibilité absolue d'identifier les participants les ayant fournies.

Participation volontaire et droit de retrait

Vous pouvez retirer de l'étude et demander que vos données supprimées jusqu'à deux semaines après que toutes les données ont été collectées. Passé ce délai, les données vont être anonymisées et, nous ne pourrions pas identifier celles comme vous appartenant, donc ne serons plus en mesure de supprimer vos données.

Compensation :

Un montant forfaitaire de 25\$ vous sera posté à la suite de l'entrevue, afin de compenser les frais/temps encourus par votre participation à ce projet de recherche.

Mandat d'inaptitude

Si la personne présentant une démence légère ou modérée fait l'objet d'un mandat d'inaptitude et que vous êtes le mandataire, vous pouvez consentir à sa participation en répondant aux questions suivantes (audio-enregistré):

- **Avez-vous bien compris le projet et les implications pour la personne que vous représentez?**
- **Désirez-vous plus de temps pour y réfléchir? Si oui, indiquez-nous le meilleur moment pour vous recontacter. Si non,**
- **Acceptez-vous de confirmer, sur cet enregistrement, que vous donnez votre consentement à la personne que vous représentez pour participer à cette étude?**

Attestation verbale du consentement pour la personne présentant une démence (en l'absence d'un mandat d'inaptitude) :

Ceci sera audio-enregistré

- **Avez-vous bien compris le projet et les implications de votre participation?**



7 jours et nuits + record 2-3 minutes au



- **Désirez-vous plus de temps pour réfléchir à votre participation? Si oui, indiquez-nous le meilleur moment pour vous recontacter. Si non,**
- **Acceptez-vous de confirmer, sur cet enregistrement audio, que vous consentez à y participer?**

REMERCIEMENTS

Votre collaboration est précieuse pour nous permettre de réaliser cette étude et nous vous remercions d'y participer.

RENSEIGNEMENTS SUPPLÉMENTAIRES:

Si vous avez des questions sur la recherche, sur les implications de votre participation, pour se retirer du projet ou pour recevoir un résumé des résultats, veuillez communiquer avec Dre Claude Vincent (chercheure responsable), au numéro de téléphone suivant : 418 529-9141 poste 6626, ou à l'adresse courriel suivante claud.vincent@rea.ulaval.ca .

PLAINTES OU CRITIQUES :

Si vous avez des plaintes ou des critiques relatives à votre participation à cette recherche, vous pouvez vous adresser, en toute confidentialité, au bureau de l'Ombudsman de l'Université Laval aux coordonnées suivantes :

Pavillon Alphonse-Desjardins, bureau 3320
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