

Science of Nursing and Health Practices
Science infirmière et pratiques en santé



Effects of an Intervention Approach Based on the Meanings of Vocal Behaviours in Older People Living with a Major Neurocognitive Disorder: A Pilot Study
Effets d'une démarche d'interventions basée sur les sens des comportements vocaux de personnes âgées vivant avec un trouble neurocognitif majeur : une étude pilote

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Volume 2, Number 1, 2019

URI: <https://id.erudit.org/iderudit/1076443ar>
DOI: <https://doi.org/10.31770/2561-7516.1029>

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Publisher(s)

Réseau de recherche en interventions en sciences infirmières du Québec (RRISIQ)

ISSN

2561-7516 (digital)

[Explore this journal](#)

Cite this article

Bourbonnais, A., Ducharme, F., Landreville, P., Michaud, C., Gauthier, M.-A. & Lavallée, M.-H. (2019). Effects of an Intervention Approach Based on the Meanings of Vocal Behaviours in Older People Living with a Major Neurocognitive Disorder: A Pilot Study. *Science of Nursing and Health Practices / Science infirmière et pratiques en santé*, 2(1), 1–15.
<https://doi.org/10.31770/2561-7516.1029>

Article abstract

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Effects of an Intervention Approach Based on the Meanings of Vocal Behaviours in Older People Living with a Major Neurocognitive Disorder: A Pilot Study

Effets d'une démarche d'interventions basée sur les sens des comportements vocaux de personnes âgées vivant avec un trouble neurocognitif majeur : une étude pilote

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Keywords

dementia;
behavioural and
psychological
symptoms; long-
term care; non-
pharmacological
interventions;
family

Abstract

Introduction: Vocal behaviours (VB) are frequent in long-term care facilities (LTCF) and have many negative consequences. Interventions to decrease VB have limited clinical impact. **Objective:** This pilot study aimed to provide preliminary evidence on the effects of an intervention approach based on the meanings of VB in older people living with a neurocognitive disorder in LTCF. **Methods:** A mixed methods action research study was used. Fourteen triads (n=43) made up of an older person who manifested VB, a family member, and formal caregivers were included. An approach based on the meanings of VB was implemented in five LTCF. Semi-structured interviews took place with some participants. Tools were used at four-time points to measure five variables: the frequency of VB, the well-being of older people, the perceived disruptiveness of VB, the partnership-based decision-making and the empowerment felt by family and formal caregivers. **Results:** The approach improved the perception of family and formal caregivers toward older people. This led to habit changes that influenced positively the frequency of VB and the well-being of older people. Formal and family caregivers also perceived VB as less disturbing and felt more empowered relatively to VB. The attitude of formal caregivers toward families evolved positively. No other changes were noted on partnership-based decision-making. **Discussion and conclusion:** This study indicates the potential of this approach to improve the well-being of older people who manifested VB, their families, and formal caregivers. This approach could be implemented in LTCF, tested and adapted for other behaviours.

Résumé

Introduction : Les comportements vocaux (CV) sont fréquents en centre d'hébergement et de soins de longue durée (CHSLD) et ils entraînent des conséquences négatives. Les interventions pour les réduire ont peu d'impact clinique. **Objectif :** Cette étude pilote visait à fournir des résultats préliminaires sur les effets d'une démarche d'interventions basée sur les sens des CV des personnes âgées vivant avec un trouble neurocognitif en CHSLD. **Méthodes :** Une recherche-action avec méthodes mixtes a été utilisée auprès de quatorze triades (n=43) regroupant une personne âgée avec des CV, un proche aidant et un soignant. Une démarche basée sur les sens des CV a été implantée dans cinq CHSLD. Des entrevues semi-structurées ont eu lieu avec certains participants. Des outils ont été utilisés à quatre moments pour mesurer cinq variables : la fréquence des CV, le bien-être des personnes âgées, la perception de dérangement des CV, la prise de décisions en partenariat, et la capacité d'agir des proches et des soignants. **Résultats :** La démarche a amélioré la perception des proches et des soignants à l'égard des personnes âgées. Cela a amené des changements d'habitudes qui ont influencé positivement la fréquence des CV et le bien-être des personnes âgées. Les proches et les soignants ont aussi perçu les CV comme moins dérangeants et ont eu une augmentation de leur capacité d'agir. L'attitude des soignants envers les proches a évolué positivement. Aucun autre changement n'a été noté dans la prise de décision en partenariat. **Discussion et conclusion :** L'étude démontre le potentiel de cette démarche pour améliorer le bien-être des personnes âgées qui manifestent des CV, celui de leurs proches et des soignants. Elle pourrait être implantée dans les CHSLD, ainsi que testée et adaptée à d'autres comportements.

Mots-clés

démence;
symptômes
comportementaux
et psychologiques;
soins de longue
durée;
interventions non-
pharmacologiques;
famille

INTRODUCTION

Responsive behaviours are frequent in older people living with a major neurocognitive disorder¹ (ND). It is the expression preferred by these people to represent their actions that express something meaningful for them (Alzheimer Society of Ontario, 2017). One type of responsive behaviours is vocal behaviours (VB) (e.g. repeating, screaming) and they can be an indication of reduced well-being. With a prevalence varying between 13% and 60%, these VB are the most frequent, persistent, and disturbing behaviours in long-term care facilities (LTCF) (Barton, Findlay, & Blake, 2005; von Gunten, Favre, Gurtner, & Abderhalden, 2011). These behaviours can have many meanings, for example, they can be the expression of unmet needs (physical, emotional, social), pain, vulnerability, and over- or under-stimulation (Algase et al., 1996; Bourbonnais & Ducharme, 2010; Sloane et al., 1997).

Few recent studies explored factors associated specifically with VB, but a classic study by Cohen-Mansfield, Werner, and Marx (1990) had found that the best predictors were cognitive impairment and quality of relationships, with also the potential influence of depression, risk of fall, lack of sleep and being restrained. In a systematic review, von Gunten, Alnawaqil, Abderhalden, Needham, and Schupbach (2008) added to these the possibility of psychosis and anxiety. VB increase the distress of the older person as well as other people sharing her environment, in addition to causing social isolation, overmedication, and higher costs for the healthcare system (Murman et al., 2002; Sloane et al., 1997).

Several interventions have been evaluated to reduce the frequency of this behaviour. Pharmacological approaches have demonstrated low efficacy for VB (von Gunten et al., 2011). They are expensive (Murman et al., 2002) and often cause side effects (Livingston, Johnston, Katona, Paton, & Lyketsos, 2005), without improving quality of life. Considering the meanings and factors associated with VB, non-pharmacological options are recommended (International Psychogeriatric Association, 2010).

EFFICACY OF NON-PHARMACOLOGICAL INTERVENTIONS TO DECREASE VOCAL BEHAVIOURS

Various systematic reviews have assessed the efficacy of non-pharmacological interventions to manage responsive behaviours, without mentioning specifically vocal behaviours (Brasure et al., 2016; Jutkowitz et al., 2016). They have shown insufficient or low-strength evidence attributed to methodological heterogeneity (e.g. various outcomes and measurements) and limitations. In a meta-analysis (n=14), Kong, Evans, and Guevara (2009) also examined the efficacy of non-pharmacological interventions on several behaviours, including VB. The only category of intervention that was shown to be effective was sensory interventions (e.g. music, aromatherapy). However, the inclusion of multi-behaviour studies makes it impossible to establish the relevancy of these interventions for VB. Furthermore, this meta-analysis showed a high degree of statistical heterogeneity ($I^2=68.2\%$) among studies on sensory interventions that may affect its validity.

In an experimental study not included in this meta-analysis, Cohen-Mansfield, Libin, and Marx (2007) evaluated the effects of individualized non-pharmacological interventions on agitation (including VB), such as music and photos. A reduction in overall agitation was noticed. A quasi-experimental study also concluded that interventions customized to the needs of each individual were more promising because of the variety of behaviours and the necessity of understanding the underlying meanings (Bird, Llewellyn-Jones, & Korten, 2009).

Studies on non-pharmacological interventions specific to VB compared the efficacy of a videotape of a family member talking to the older person, social interactions, and the use of music (Cohen-Mansfield & Werner, 1997) as well as care strategies regrouped in the categories of sensory intervention: social contact, behavioural therapy, structured activities, environmental intervention and pain/restraint management (von Gunten et al., 2011). However, these studies showed a limited clinical impact since VB resumed immediately after the intervention (Cohen-Mansfield & Werner, 1997) or the interventions were being underused by staff (von Gunten et al., 2011). Based on a

systematic review (n=8) of non-pharmacological interventions for VB, Randall and Clissett (2015) recommended rigorous study of individualized interventions that combine several approaches and that involve training staff to identify the reasons or meanings for the VB.

In the studies reviewed, the interventions were applied by the research staff, thus reducing the external validity of the intervention. Furthermore, the significant effects did not persist beyond experimentation and, in several studies, responsive behaviours were grouped together not allowing to distinguish the specific effects of these interventions on VB. Finally, these studies did not take into consideration the well-being of older people nor the impact of VB on family and formal caregivers, which in turn can affect older people's behaviours (Dupuis, Wiersma, & Loiselle, 2012; Graneheim, Isaksson, Ljung Persson, & Jansson, 2005). However, VB are described as disturbing for family and formal caregivers. This can affect their well-being and sense of empowerment when faced with this behaviour (Barton et al., 2005; Graneheim et al., 2005).

In light of these findings, a study led to developing an intervention approach based on the meanings of VB in older people living with ND (hereinafter called 'the approach') (Bourbonnais & Lavallée, 2014). As recommended by Bird et al. (2009) and Randall and Clissett (2015), this approach sought to optimize the use of non-pharmacological interventions. It describes how to identify the meanings of VB using strategies that lead to decision-making in partnership with family and formal caregivers and how to associate these meanings to multiple individualized interventions. However, this project was conducted in partnership with only one nursing care unit with the aim of developing the intervention. As such it did not result in a systematic implementation in LTCFs or allowed to evaluate its efficacy. The pilot study presented in this article was therefore designed for this purpose.

OBJECTIVE

The objective of this pilot study was to provide preliminary evidence on the effects of this approach on older people living with ND in LTCF and manifesting VB, their family and formal

caregivers. Another objective of this pilot study was to assess the feasibility and acceptability of the implementation of this approach. These results are presented elsewhere (Bourbonnais et al., 2018; Bourbonnais et al., 2017).

METHODS

A mixed methods action research with a convergence triangulation was used (Creswell & Plano Clark, 2007; Heron & Reason, 1997). This method took the strategies for implementing the approach a step further while also assessing its effects. The evaluation of the effects was carried out from quantitative and qualitative data collected simultaneously from the same participants, then analyzed separately and compared to confirm or complement qualitative results against the quantitative findings (Creswell & Plano Clark, 2007). For the quantitative component, a pre-experimental design was used where all participants received the intervention. Pretest, two intermediary and post-test measures were taken. The qualitative component of the study was based on the qualitative outcome analysis method described by Morse, Penrod, and Hupcey (2000) that uses multiple sources of data to qualitatively assess an intervention. Data were obtained at the post-test time point with some family and formal caregivers.

INTERVENTION APPROACH

Developed in a previous study (Bourbonnais et al., 2013), the approach respects the current recommendations for non-pharmacological interventions for VB (Bird et al., 2009; Randall & Clissett, 2015) and is innovative in that it calls for work in partnership with family and formal caregivers, using a problem-solving process based on the meanings of VB. The approach aims to reduce the manifestations of VB in older people and increase older people's well-being, as well as to improve the sense of empowerment of family and formal caregivers. It is based on five principles: i) partnership between the older person, the family, and the formal caregivers; ii) identification of the meanings of VB (e.g. pain, anxiety, lack of

control, dissatisfaction); iii) use of many interventions, either evidence-based or imagined in partnership; iv) tailoring of interventions; and v) active team-based reflection. To operationalize these principles, family and formal caregivers met at least once a month for three months and worked together between these meetings to carry out six steps. The six steps were:

- 1) combining identification strategies for the meanings of VB (e.g. family and formal caregivers think of events that occur on the care unit and seem to influence the older person);
- 2) identifying the possible meanings of VB (e.g. the older person has emotional needs related to feeling anxious);
- 3) associating categories of interventions to each meaning (e.g. the emotional needs can be associated with communicative and socioaffective categories of interventions);
- 4) imagining or selecting specific interventions for each intervention category (e.g. for the socioaffective category, the simulated presence of a relative could be initiated and the older person could be seated next to a resident that is liked);
- 5) identifying people responsible for each intervention (e.g. the nurses' aide is responsible for setting her up for the simulated presence); and
- 6) readjusting interventions (e.g. a new meaning is identified with the son of the older person; formal and family caregivers plan together interventions based on this meaning) (Bourbonnais & Lavallée, 2014).

Using these steps, various meanings were identified for each older person who participated in the study (e.g. wanting to return home, being scared) and multiples individualized interventions were applied (e.g. reminiscence activities, gardening). A complete listing of the meanings (> 20) identified by the participants and of the interventions used by them (> 50) is available elsewhere (Bourbonnais et al., 2017).

Various strategies were used to ensure the fidelity of the approach during implementation. This fidelity was based on the respect of the five principles of the approach and was documented weekly by the study coordinators with an open-

ended questionnaire. The implementation strategies involved, among other things, a seven-hour training session, case history synopses, using formal caregivers as local leaders, and regular follow-up on the implementation by registered nurses (RN) with master's degrees who served as study coordinators. These strategies are described elsewhere (Bourbonnais et al., 2018).

SAMPLE

Participants were recruited in five LTCF in the Greater Montreal area (Canada). Since statistical power is not expected in a pilot study, some authors (Hertzog, 2008; Julious, 2005) mention that at least 12 participants per group can be sufficient. The sample (n=43) was therefore made up of triads including an older person who manifested VB (n=14), a family member (n=14), and one or two formal caregivers (n=15). The inclusion criteria for the older people were to have a ND, to manifest daily VB, and to have contact with a family caregiver. Family caregivers had to offer the older person support, have knowledge of the person's life story, and visit her once a week. Formal caregivers were RNs, licensed practical nurses (LPN), nurses' aides, or special education instructors who were involved in the older person's care at least three times per week. The eligibility was ascertained by the study coordinators with the help of head nurses and formal caregivers. For the qualitative component of the study, the sample size was determined by data saturation. Three family caregivers and three formal caregivers were recruited with a convenience sampling method among participants from the quantitative component. With these participants, data saturation was achieved, i.e. data richness was reached, and no new information was obtained which led to stop the recruiting (Morse, 1995). The participants included in this part of the study were the ones most capable of sharing with ease their perceptions on the effects of the approach. This was ascertained by the study coordinators during the implementation of the intervention.

DATA COLLECTION

For the quantitative component, various tools for each type of participants were used to take

identical measures four times: before starting the approach (T0-preintervention), after one month (T1), after two months (T2), and after three months (T3). These measures were carried out by interviewers during in-person meetings.

Measures relating to older people. The frequency of VB was measured with the Cohen-Mansfield Agitation Inventory (CMAI), based on 29 behaviours observed by a formal caregiver over the past two weeks (Cohen-Mansfield, 1991). A factor analysis revealed three subgroups of behaviours with a distinct score (Cohen-Mansfield, 1991). The score of the subgroup Verbally Agitated Behaviours was used. This tool has a Cronbach's alpha between 0.75–0.91 and an inter-rater reliability between 0.72–0.92 (Cohen-Mansfield, 1991; Deslauriers & Landreville, 2001).

Well-being was measured with the Quality of Life in Late-Stage Dementia (QUALID) (Weiner et al., 2000) questionnaire, which measures 11 observable well-being behaviours as assessed over the past 7 days by a formal caregiver on a scale of 1 to 5 (Cronbach's alpha of 0.77, test-retest of 0.81, and inter-rater reliability of 0.83) (Schölzel-Dorenbos, Krabbe, & Rikkert, 2010).

To describe the cognitive impairment at T0, the Mini-Mental State Examination (MMSE) was used. A score greater or equal to 24 indicate normal cognition (Folstein, Folstein & McHugh, 1975).

Measures relating to family caregivers. The disruptiveness scale of the CMAI was used to measure family caregivers' perceptions of VB disruptiveness. It rated how disruptive each behaviour of the CMAI is. Partnership-based decision-making was measured with the Family Perception of Caregiving Role (FPCR) questionnaire (Maas et al., 2004). This assesses the quality of the interactions between family and formal caregivers in LTCF. The 23 items of the subgroup 'Partnership Interactions' were used. Cronbach's alpha is 0.70–0.84 (Maas & Buckwalter, 2015b).

One question was used to measure the sense of empowerment of family caregivers ('When my relative manifests VB, I feel I can do something for him/her') on a visual analogue scale from 0 ('I feel that I cannot do something for him/her') to 100 millimeters ('I feel I can always do something for him/her'). This type of single-item scale has been

demonstrated to be valid, reliable, and responsive to changes on various topics such as quality of life and depression (Bowling, 2005; de Boer et al., 2004; Hürny et al., 1996).

Measures relating to formal caregivers. The disruptiveness scale of the CMAI was also used with formal caregivers (Cohen-Mansfield, 1991). Partnership-based decision-making was measured using the Staff Perception of Caregiving Role (SPCR) (Cronbach's alpha 0.70–0.94), which is parallel to the FPCR. The 26 items of the subgroup 'Partnership with the Family' was used (Maas & Buckwalter, 1993). The Attitudes about Families Checklist (AFC) was also used to measure the attitude of formal caregivers in regard to families' participation in decisions and care (Cronbach's alpha 0.75–0.91) (Maas & Buckwalter, 2015a). To assess empowerment, the same single question was asked.

For the qualitative component of the study, individual interviews were held at T3 with some family and formal caregivers. A semi-structured interview guide addressed major topics on the effects of the approach. A version of the interview guide was designed for family caregivers and another for formal caregivers. An example of a question is 'If your relative/the older person could describe her/his well-being in the last months, what would she/he tell us? What would she/he say now?' The study coordinators also kept a journal describing relations with participants and the implementation process of the approach.

DATA ANALYSIS

Qualitative and quantitative data analyses were performed separately, and then the results were compared in an interpretation stage (Creswell & Plano Clark, 2007). As the sample for the qualitative part of the study reached data saturation and the quantitative results were expected to mostly show trends in the effects because of the small sample, the themes that emerged from the qualitative analysis were used as a template for comparing and integrating quantitative results. During the process of comparison, the quantitative results were qualified as either congruent or complementary to the qualitative results.

Qualitative analysis. Qualitative data analysis was based on strategies by Miles, Huberman, and Saldaña (2014). Inductive coding was carried out by one team member and reviewed by another. Then, the data were grouped to bring out similarities. These categories were integrated into a comparison matrix to bring out the divergent findings between the perspectives of family and formal caregivers. The themes were refined by two members of the team.

Quantitative analysis. To obtain the trends in the effects, ordinal and continuous variables were analyzed with Student's t-tests for paired samples by comparing T0 and the other time-point measures. Given the pilot nature of the study and the small sample, graphs of the results at the four-time measures are presented for visual inspection, and no comparison between the groups of participants or missing-data imputation was made. SPSS version 23 (IBM Corp., 2015) was used.

ETHICAL CONSIDERATIONS

The research protocol was approved by the Institutional Board Review, and written informed consent was obtained from participants. Considering the cognitive impairment of older people, family members who consented to their care gave consent for their participation in the approach. Unique identifiers were used to ensure confidentiality.

RESULTS

SAMPLE DESCRIPTION²

The older people in the sample were in average 87.5-year-old (standard deviation [SD] 5.8) and 8 out of 14 were women. They had been manifesting VB for the last 4 to 120 months. The older person who had manifested VB for 120 months had a psychiatric comorbidity. Their cognitive impairment was severe as measured with the MMSE (2.83 on 30, SD 3.9, range 0 to 12). Twelve out of 14 family caregivers were women and they were in average 59.6-year-old (SD 9.7) with an average of 15 years of education (SD 3.1). Two of them were not a blood relation of the older person but were very involved with her care. The

others were spouse, children, brother/sister or a niece. In one triad, a different formal caregiver participated at three of the time-points. Formal caregivers were in average 48.5-year-old (SD 11.2) and 13 out 15 were women. Four were RN with a college diploma, 2 were LPN, 7 were nurses' aides, and 2 education instructors. Twelve worked during the day shift and three on evening. They had on average 19 years (SD 8.7) of clinical experience.

Given the frailty of the older people recruited for this study, a loss of 30–40% was anticipated. During the study, four participants died, and one family caregiver decided to withdraw from the project, making for a sample loss of 36%. Full data were obtained for nine triads, and the quantitative data analysis were performed on these triads.

FINDINGS

Qualitative and quantitative results are jointly presented. A summary of both forms of results is displayed in Table 1. The nature of the contribution of quantitative results to the qualitative ones is also indicated. The description of the two themes and their subthemes are now presented. The first theme describes a new perception of the older person and the second one the creative process grounded in habit changes that influence the triad. This second theme integrates the quantitative results.

1. A new perception of the older person through being attentive with renewed curiosity. Following the implementation of the approach, family and formal caregivers perceived the older person differently. They felt closer and understood her better. This renewed perception can be explained by two subthemes.

1.1. Learning to know the older person better through attentiveness. For the formal caregivers, meetings with family caregivers were key to getting to know the older person better. By holding a common goal of understanding the older person's behaviours, the formal and family caregivers were more attentive to her preferences. This new interest in knowing older people led them to treat them more as a human being. Family and formal caregivers spoke to them more and were more attentive to their needs. One of the formal caregivers explained this as follows:

Table 1
Summary of findings

Qualitative themes and subthemes	Quantitative outcomes	Contribution of quantitative results to qualitative results
1. A new perception of the older person through being attentive with renewed curiosity		
1.1. Learning to know the older person better through attentiveness	N/A	N/A
1.2. Being curious to understand the older person	N/A	N/A
2. Creative process grounded in habit changes that influence the triad		
2.1 Changes in the older person		
2.1.1. Sometimes I scream less; sometimes I don't scream anymore	Frequency of vocal behaviours: trend toward improvement	Congruent
2.1.2. Well-being of the older person: I feel better	Well-being: trend toward improvement	Congruent
2.2. Changes in formal and family caregivers		
2.2.1. For formal caregivers, the VB became less disruptive; for family caregivers, they were mostly troubling	Perceived disruptiveness of formal caregivers: trend toward improvement	Congruent
	Perceived disruptiveness of family caregivers: trend toward stability	
2.2.2. Now we know how to be and what to do	Formal caregivers' empowerment: trend toward improvement	Congruent
	Family caregivers' empowerment: trend toward improvement	
2.2.3. We know each other more. We sometimes get along better	Formal caregivers' attitudes toward families: trend toward stability, except for the attitude about the contribution of families that shows a trend toward improvement	Complementary
	Formal caregivers' perception of partnership with families: trend toward stability	
	Family caregivers' perception of partnership with formal caregivers: trend toward stability	

N/A: Not applicable

“It developed our awareness that even if you have Alzheimer’s, you’re still human. You have to dig deep to discover those individuals [...]. We got wondering about them, what they liked or didn’t like, why they scream. It prompted us to talk to them more.”

This new attention led to a vision of the older people from a new angle and this in turn led to an interest in understanding the meanings of their VB.

1.2. Being curious to understand the older person. Family and formal caregivers were curious to better understand the older person. They mentioned trying to imagine themselves in the older person’s shoes. This allowed them to identify the meanings of the VB and increase their empathy for this person. These efforts reoriented their concerns, which were initially focused on others’ perception of the behaviour. One of the family caregivers explains:

“In the beginning I can definitely say it disturbed me. I’m not sure if it was because of what others would think or because I myself was uncomfortable with his screams. This changed because I understand more what’s really going on in his head. I figure that if he screams, it’s because he’s unhappy. I don’t like seeing him unhappy. That bothers me. But it’s no longer about what other people will think like it was at first.”

Sometimes, this change has led certain family caregivers to rediscover the older person as they knew her before being admitted to the LTCF. This curiosity brought about formal and family caregivers to mention learning the ‘language of the VB’. To learn it, they often went by trial and error with their interventions, after having identified a possible meaning to the VB.

2. Creative process grounded in habit changes that influence the triad. Family and formal caregivers described changes in their practice via a creative process that made it possible to influence both the older person who manifests VB and the formal and family caregivers themselves. The quantitative results show a trend corroborating these changes as described below.

These participants confirmed that the approach helped them explore more systematically the meanings of the VB. According to them, these meanings helped them think of new

interventions. As for the formal caregivers, they reported changes in their habits by involving the families much more.

2.1. Changes in the older person. Changes were perceived in the frequency of VB of older people, as well as in their well-being. They are described in the following qualitative subthemes and complemented by the quantitative results.

2.1.1. Sometimes I scream less; sometimes I don’t scream anymore. The family and formal caregivers reported a reduction in the frequency of the VB during qualitative interviews. Without the behaviour necessarily stopping altogether, they assessed the clinical improvement as being significant, as described by a formal caregiver:

“The screams aren’t quite a language, but there’s the type of scream and the timing of it. We started with the basic needs, and the screams stopped by 85–90%.”

This statement was corroborated by quantitative results. These showed a strong trend of progressive improvement at T2 ($p=0.047$) and T3 ($p=0.019$) (see Figure 1).

2.1.2. Well-being of the older person: I feel better. The approach seems to have had positive effects on the older people’s well-being. It was observed that certain older people appeared to be more serene. One of the family caregivers said the following:

“I know that now she is more... not in better physical shape, but happier and calmer. I think that’s already a lot. It’s like I can see my mother as she was before.”

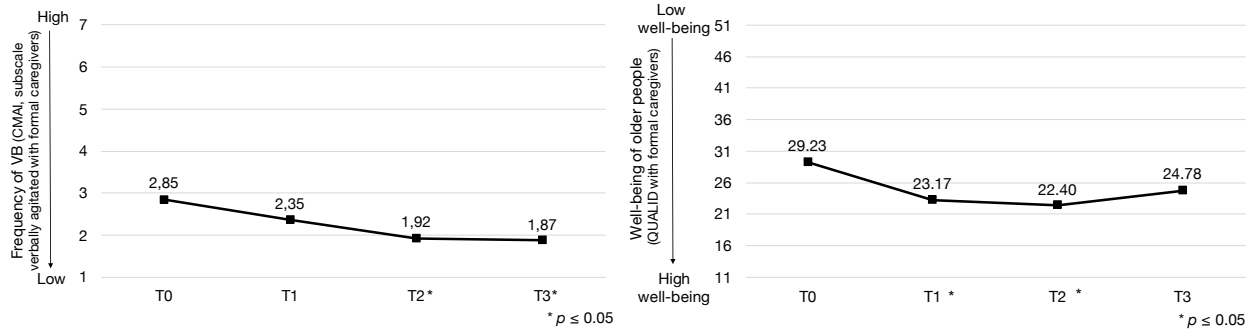
Others considered that the older people’s well-being had increased since some seemed comforted or less anxious. In other cases, they seemed to even have a better skin tone and to laugh instead of manifesting VB as report one of the family caregiver:

“Now with the project [...], I find she laughs. It’s really like night and day. I think she has even more colour, you know, it is not makeup, she is pink. Before, it seems to me [her complexion] was dull, gray.”

This effect on older people’s well-being was corroborated by measurement with the QUALID. A progressive trend toward improvement was noted at T1 ($p=0.037$) and T2 ($p=0.017$).

Figure 1

Outcomes about changes in the older person: frequency of VB and well-being



At T3, the results indicate a slight decrease in well-being compared to T1 and T2 ($p=0.172$). However, the well-being at T3 still appears higher than at T0 (see Figure 1).

In light of the qualitative results where participants also observed an improved well-being, it would seem that the difference is clinically significant.

2.2. Changes in formal and family caregivers.

Changes were also observed in formal and family caregivers.

2.2.1. For formal caregivers, the VB became less disruptive; for family caregivers, they were mostly troubling. Before the approach, the VB were troubling, rather than disturbing, for the families because they feared the behaviour would disturb others. The quantitative results were coherent with this qualitative result by showing some stability in the disruptiveness perceived by family caregivers (see Figure 2).

For their part, formal caregivers were disturbed and reported finding VB less disturbing after the approach was implemented:

“Before, it bothered me. But now, I don’t find it disruptive because I know that when he screams it’s because of a need. But before, I thought he was screaming just to scream.”

The quantitative results corroborate this trend. In formal caregivers, the results show a trend of improvement in the perceived disruptiveness at T2 ($p=0.045$) and at T3 ($p=0.066$) (see Figure 2).

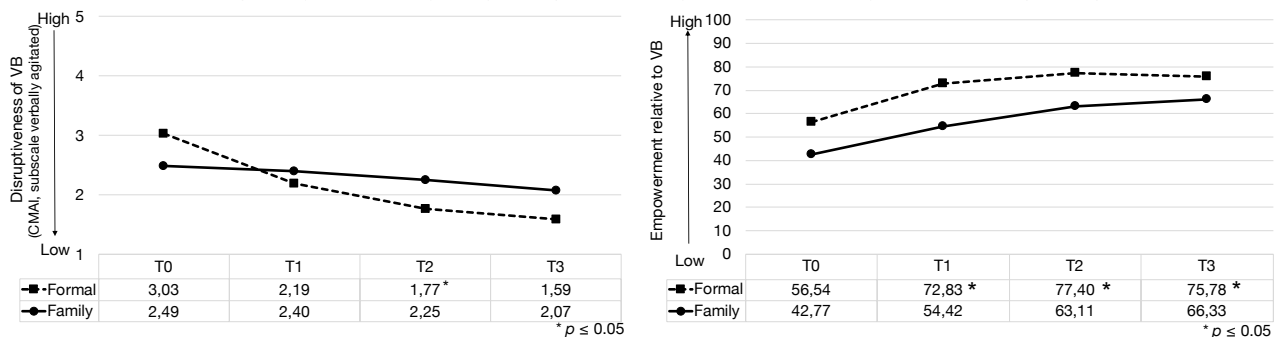
2.2.2. Now we know how to be and what to do.

The family and formal caregivers reported feeling more empowered to do something about the VB. Many formal caregivers used the approach with other older people and consider it a tool for better interventions. One of the observations was that it helped them provide care in a timely manner, rather than take more time. For family caregivers, the approach increased their confidence in how to be with the older person.

The quantitative results confirm this increased empowerment. In formal caregivers, a marked trend toward an increased sense of empowerment was noted starting at T1 ($p=0.03$) and continued until T3 ($p=0.043$) (see Figure 2). The visual

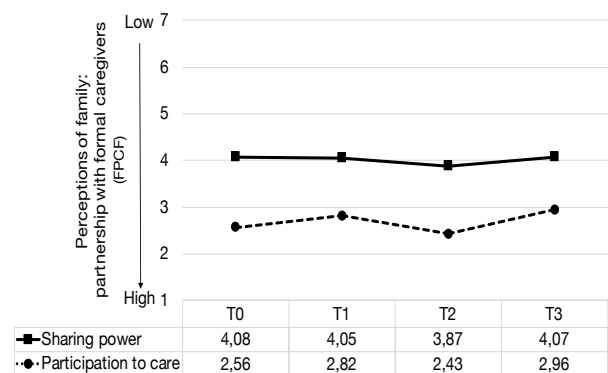
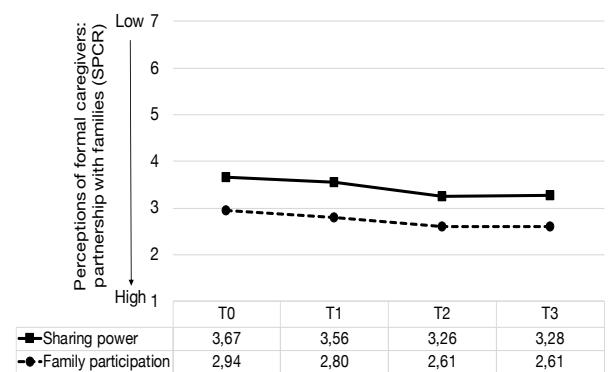
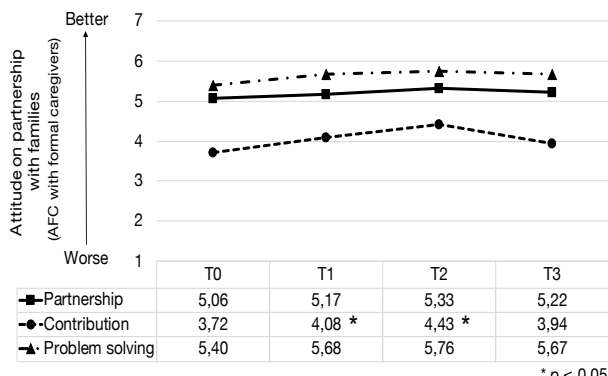
Figure 2

Outcomes about changes in formal and family caregivers: disruptiveness and empowerment regarding VB



inspection of data for family caregivers also indicates a trend toward improvement, although the evolution was not statistically significant as might be expected in a pilot study.

Figure 3
Outcomes about changes in formal and family caregivers: attitudes and perceptions on partnership



2.2.3. We know each other more. We sometimes get along better. Family caregivers highlighted that the approach made it possible to share a common goal with the formal caregivers, which facilitated their interactions. Some spoke of sharing closeness. Formal caregivers also showed more interest in the families' well-being:

"They [the formal caregivers] were closer to me. When I'd arrive, they would come see me right away. They'd ask me how I was, how I managed earlier, how my mother is."

In some triads, family trust in the formal caregivers increased. The formal caregivers saw that families were less shy in asking questions and more comfortable discussing issues with them. In other cases, family caregivers observed few changes in formal caregivers' manner with the older person. Sometimes, family caregivers felt they were more concerned about the older person's well-being than the formal caregivers.

The quantitative results complemented these ambivalent effects in the partnership-based decision-making. The formal caregivers' attitude toward partnership with families was mostly stable with a slight improvement at T2 ($p=0.057$) (see Figure 3). A trend toward improvement in their attitude regarding family members' potential contribution was noted at T1 ($p=0.043$) and at T2 ($p=0.01$), but decreased at T3, without returning to baseline. Few changes were noted in their attitude with regard to families' ability to solve problems in partnership. These results are in line with the qualitative results, which indicate that formal caregivers found families' contributions helpful as a source of information, though they did not necessarily take actions that would favour family involvement in the care. There was little change in formal caregivers' perception of sharing decision-making power and families' participation in care. Family caregivers' perception of sharing power and participation in care was also stable.

DISCUSSION

This mixed pilot study made a preliminary demonstration of the efficacy of the approach. The qualitative results showed that the approach was perceived by formal and family caregivers as having positive effects on older people, family and formal caregivers. Based on the qualitative and quantitative findings, no adverse effects were noted such as an increase in medication use or distress in family caregivers. The quantitative results were congruent with the qualitative results and showed a trend toward improvement on all

variables except on partnership decision-making where results were mostly stable.

These results were based on a sample of older people who had characteristics similar (severity of cognitive impairment, age) to the ones found in LTCF of various countries (Cohen-Mansfield & Werner, 1997; Matthews et al., 2016; Røen et al., 2017), except for gender. In these studies, 64 to 81% of participants were women. This proportion was lower in our sample (57%) as one of the LTCF cared for veterans. Our attrition rate was alike the one in these studies.

One of the effects of the approach seems to be a change in family and formal caregivers' perspective of the older person. This change in perspective was associated by participants with a clinically significant reduction in the frequency of VB after two months of use, as well as the improvements in older people's well-being. The quantitative results corroborated this trend toward improvement. These effects confirm the potential of the approach to affect the older person's overall experience. Moreover, the VB were seen as less disruptive for formal caregivers. There was a lesser effect on family caregivers, who showed low levels of feeling disturbed from the start. Families' shorter periods of contact with the older person could explain this lesser initial level of the perceived disruptiveness of the VB. Also, when the older person manifested VB, qualitative and quantitative results both demonstrated that the formal and family caregivers felt more empowered. This empowerment shows an effect on the well-being of caregivers, regardless of the frequency of the VB.

The changes in family and formal caregivers' perspective of the older person can be associated with an increase in empathy, which contributed to a progressive change of culture in the LTCFs from a task-based approach to a person-centred approach (Ronch, 2004). This change of culture was also reflected in the positive effects of the approach on formal caregivers' sense of empowerment. According to Caspar and O'Rourke (2008), this effect, in particular that of nurses' aides, could be associated with a more individualized offer of care.

The results regarding partnership were the most ambiguous. The qualitative results indicated that this partnership took place between some

formal and family caregivers, but not as much between others. This is congruent with the quantitative results showing that the attitude of formal caregivers toward families evolved in a positive trend. However, power sharing between the formal and family caregivers was relatively stable in time. This is consistent with a qualitative study that examined the experience of formal caregivers (n=30) working with families in LTCF (Bauer, 2006). Despite a recognition of the value to work with families, these participants were ambivalent about the involvement of families, especially regarding sharing power in deciding and offering care. This ambivalence was explained as a belief of formal caregivers that care should be under their control. For them, the role of families was to share their biographical knowledge of the resident to facilitate their care, not to decide the relevant care. This author hypothesized that formal caregivers might not have the confidence to involve family in partnership-based decision-making or might lack training working with families. However, it might be possible to train caregivers to work with families.

In a quasi-experimental study of 185 families and 895 formal caregivers of older people with cognitive impairment living in LTCF, Maas et al. (2004) evaluated the efficacy of an intervention to foster family involvement in a partnership, using the same tools as those used in this study (FPCR, SPCR, and AFC). Their results show that formal caregivers perceived families to be less bothersome and more useful in the care. The relevancy of the contribution to care was also improved in our study. Concerning the sharing of decision-making power in our study, little changes were noted, contrary to the positive results of Maas et al. (2004). It is possible to hypothesize that by further supporting formal caregivers in partnership creation as in Maas et al.'s study, the effects on this aspect of the approach could be increased.

STRENGTHS AND LIMITATIONS

The credibility of our results is reinforced by multiple triangulation. Our sample included various types of formal caregivers with a variety of characteristics. Furthermore, this diversity was combined with a triangulation of the participants,

the settings, and the data collection and analysis methods. As recommended by the author of the CMAI (Cohen-Mansfield, 1991), the subscale of verbal behaviour was used. This made it possible for us to show the effects specific to VB rather than obtain an overall agitation score.

One of the limitations of this pilot study relates to the small sample size that was influenced by a high attrition as anticipated in this population of older people. This limit was lessened by the mixed design that allowed us to compare the quantitative results with the qualitative ones. Another limitation concerns the lack of a control group, which keeps us from determining to what extent the observed changes resulted from the approach. We faced many obstacles during recruitment, including a restructuring of the healthcare system during the study. These difficulties kept us from recruiting additional triads to replace those lost after a death. Despite these setbacks, we obtained useful indications on the possible effects of the approach on older people.

IMPLICATIONS

Since there is little evidence of effective interventions and that our approach is without adverse effects, while having potential positive effects on the frequency of VB, well-being and empowerment, the approach could be implemented in LTCF to improve quality of care and fully assess. The results also underline the difficulty of formal caregivers to work in partnership with family caregivers. This ability could be strengthened in LTCF. It would be relevant to conduct studies to assess the effectiveness and cost of the approach in comparison to usual care and with larger samples. The project's time points led us to identify that changes could be clinically detected two months after the implementation. We also recommend furthering the understanding

of the behaviours of older people with ND by examining one type of behaviour at a time to identify specific interventions that are effective.

CONCLUSION

The approach seems to have beneficial effects on the behaviours and well-being of the older people participating in the study and on that of their caregivers. It increased empathy and contributed to a shift in LTCF's culture to focus on individualized care. This suggests that this approach could potentially improve the quality of clinical practices in LTCF.

Authors' contribution: We applied the sequence-determined credit approach for the sequence of authors. AB designed and managed the study, contributed to the data analysis and the interpretation of the results, wrote the first draft of this manuscript and revised it. FD, PL and CM critically reviewed the research protocol, helped refined it, helped manage the study, contributed to the interpretation of the results and revised the manuscript critically. MAG and MHL implemented the intervention, coordinated the data collection, contributed to the data analysis and revised the manuscript critically.

Acknowledgments: We wish to thank the older persons, the family and formal caregivers, and the managers of the long-term care facilities who generously took part in this project.

Funding: This work was supported by the Alzheimer Society of Canada.

Conflicts of interest: The authors declare no conflict of interest.

Ethical considerations: The study received ethical approval CER-IUGM-13-14-011 from the research ethics board of the Research Centre of the Institut universitaire de gériatrie de Montréal.

ENDNOTES

1. Major neurocognitive disorders include Alzheimer's, vascular, mixed, frontotemporal, and Lewy body disease.
2. Given the predominance of women in the sample, the feminine form is used to apply to both genders.

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