An intervention approach to optimize the well-being of older people living with Alzheimer’s disease who scream: Results of an action research

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Problem

• 80% of older people in a long-term care facility (LTCF) live with Alzheimer’s disease or a related disease

• Among them, 15 to 60% scream

Definition of screams

• Vocal behaviour that does not seem appropriate in the context

• Observed by people within the environment

• Intensity, frequency and duration vary
Interventions mentioned in the literature

- Biomedical treatment
- Behavioural approaches
- Modifying the physical environment
- Modifying the social environment
- Using multiple interventions

Lack of efficacy: interventions are not based on the meanings of screams

(Christie & Ferguson, 1988; Cohen-Mansfield, Libin, & Marx, 2007; Cohen-Mansfield & Werner, 1997; Doyle, Zapparoni, O’Connor, & Runci, 1997; Ramadan & Naughton, 1999)

But...

- Strategies to identify meanings of screams and to associate them to an intervention are not known

Hinder the development and implementation of helpful interventions
Goal

- To develop and evaluate interventions based on the meanings of screams of older people living with Alzheimer’s and related diseases

Project in 2 phases

1. Conceptualization of a process to identify the meanings of screams by formal caregivers with family members
2. Development and evaluation of interventions based on these meanings

Method: Participatory action research

- To plan and apply an intervention with the people concerned by the problem
- To improve a professional practice with the participants
- To link research and practice
- To change the actual condition of the clinical setting

(Reflected on Waterman’s 2001 model)
Sample: 8 triads

- **Older people**
  - Manifesting vocal behaviours
  - Having a diagnostic of Alzheimer's disease or a related disease

- **Family caregivers**
  - Being a main caregiver of the older person

- **Formal caregivers**
  - Being a registered nurse (RN), a registered nursing assistant (RNA) or a nurse's aide (NA)
Sociodemographic characteristics

- **Older people (n = 8)**
  - Mean age: 89.5 years old (SD = 4)
  - \( \varphi : 5 \quad \varnothing : 3 \)
  - Dementia severity: 6 / 8 = moderate or severe

- **Family caregivers (n = 10)**
  - Mean age: 62.6 years old (SD = 17)
  - \( \varphi : 7 \quad \varnothing : 3 \)
  - Daughter / son (5), spouse (1), nephew / niece (2), other (2)

- **Formal caregivers (n = 17)**
  - Mean age: 48 years old (SD = 10)
  - \( \varphi : 12 \quad \varnothing : 5 \)
  - RN (4), RNA (2), NA (10), other (1)
  - Average years of practice with this population: 13 years (SD = 11)

Data collection

- **Group interviews with:**
  - one or more family members of an older person who screamed
  - an RN working with this older person
  - other formal caregivers (RNA, NA, recreation therapist)
  - using semi-structured interview guides
  - Participants and researchers journal
  - Sociodemographic questionnaires
Data analysis

- Qualitative approach
- Instrumental case study
  - 1 case = 1 triad
  - Chosen to understand a phenomenon better
- Analysis strategy
  - intratriad
  - intertriads

Data Analysis

Data reduction
Verification of results
Representation of similarities and differences

Results:

A multicomponent intervention approach

Ingredients
Components
Actions

(Miles & Huberman, 2003; Stake, 2000)
(Sidani, 2011)
Results:
Intervention ingredients

- Partnership in triad
- Searching for the meanings of the behaviour
- Using multidimensional interventions coherent with the meanings
- Personalization of interventions
- Reflective practice

Results:
Intervention components

1. Strategies to identify the meanings of screams
   - Exploratory, deductive, collaborative, reflective
2. Possible meanings of screams
   - Needs, stimulation, insatisfaction, discomfort ...
3. Categories of intervention
   - Socioaffective, cognitive / communication, behavioural / leisure
4. Specific interventions
   - Reminiscence, humour, music ...
5. Actors applying the interventions
   - Other residents, family, staff, volunteers ...
6. Reflective process and readjustment of interventions
## INGREDIENTS

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<tr>
<th>COMPONENTS OF INTERVENTIONS APPROACH</th>
<th>ACTIONS</th>
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| 1. Strategies to identify the meanings of screams | 1.1 Prerequisite  
1.2 Combine identification strategies  
1.3 Organize team meeting including family member(s) |
| 2. Possible meanings of screams | 2.1 Identify the meanings of screams in partnership |
| 3. Categories of intervention | 3.1 Associate each meaning with an intervention category in partnership |
| 4. Specific interventions | 4.1 Imagine specific interventions for each intervention category in partnership |
| 5. Actors applying the interventions | 5.1 Associate a maximum of people (other resident, family, staff, etc.) to execute the interventions in partnership  
5.2 Share with these people the interventions  
5.3 Follow-up on the implementation and effects |
| 6. Reflection and readjustment of interventions | 6.1 Organize another team meeting including family member(s) |

### Results: Perception of effects on screams and other people

- From the perspective of family and formal caregivers:
  - scream of older person: slightly to completely
  - well-being of older person
  - disruptiveness for family and formal caregivers
  - empowerment of family and formal caregivers
  - partnership between family and formal caregivers
Mrs. Rachel’s nurse’s aide to her daughter

I could probably say [she is screaming less] at night because of the environment. When we turn her [in bed], there is now a picture of her brother, yes, once we turn her, she gets very quiet, she is relax. It is more like a home for her now. It helps calm her down.

Results: Involvement of participants in knowledge transfer

• Results on intervention components written up as an exemplar:
  • “Mrs. Adrianna, her daughter and a professional caregivers”
• Nurse’s aides volunteered for a public reading/playing of the exemplar to colleagues
• Triggered discussion on:
  • results
  • knowledge transfer into professionnal practice
Conclusion

- Promising intervention approach to increase well-being of older people, family and formal caregivers in LTCF
- Contributes to increase partnership between family and formal caregivers
- Effects will be formally evaluated in coming research projects:
  1. Pilot study
  2. Practical clinical trial

I will be happy to answer your questions

Thank you!