The social positioning of older people living with Alzheimer's disease who scream in long-term care homes

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Abstract

This article describes the social positioning of older people living with Alzheimer's disease who scream in a long-term care home. Few studies have focused on the social positions taken by older people, their family and formal caregivers during interaction and their effects on screams. A secondary data analysis was conducted using Harré and Van Langenhove's positioning theory. The results show that older people are capable of positioning and repositioning themselves in relational patterns. Family and formal caregivers position older people who scream according to their beliefs about their lived experience. They also react emotionally to older people and try to influence their behaviors. Understanding the social positioning of older people with Alzheimer's disease brought out their capacities and their caregivers' concerns for their well-being. Interventions should focus on these strengths and on promoting healthy relations in the triads to enhance quality of care in long-term care homes.

Keywords: agitation, critical ethnography, dementia, nursing home, positioning theory.

Introduction

People scream for various reasons, i.e. out of joy, rage or fear. Whether it be newborn babies, women giving birth or even various animals, screaming is used to convey a powerful message. It is therefore not surprising that older people living with Alzheimer's disease[1] also express themselves through screaming, especially since they very often have limited means of communicating their needs and experiences.

In long-term care (LTC) homes, 60% to 90% of older people are living with Alzheimer's disease or a related disorder (Canadian Institute for Health Information, 2012; Canadian Union of Public Employees, 2009; Conseil des aînés, 2007; Lithgow, Jackson, & Browne, 2011; Matthews & Dening, 2002; Staples & Wodak, 2008) and of these, many scream (Cohen-Mansfield, Werner, & Marx, 1990; Ryan, Tainsh, Kolodny, Lendrum, & Fisher, 1988). It is difficult to know the prevalence of screaming in LTC homes since this behavior is often labeled under neuropsychiatric symptoms or agitation. Some studies indicate that between 48% to 82% of older people living in LTC homes present with verbal agitation (Margallo-Lana et al., 2001; Youn et al., 2011; Zuidema, Koopmans, & Verhey, 2007).

In order to clearly distinguish screaming from other agitated behavior, it is defined here as vocal behavior that is heard by others (Cohen-Mansfield, Marx, & Werner, 1992). Screaming can have various meanings (Bourbonnais & Ducharme, 2010; Hallberg & Norberg, 1990) and be associated with several different factors (Cohen-Mansfield, et al., 1992; Cohen-Mansfield, et al., 1990).

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[1]All references to Alzheimer's disease also include related disorders.

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Regardless of the meanings associated with it, screaming is a common communication behavior in LTC homes. It occurs in a social context involving several people who can influence its occurrence. As it is particularly difficult for family caregivers and health care professionals to ignore or avoid, this communication behavior inevitably elicits a reaction from other people in the care environment. However, very little research has been done on the relational and social aspects of communicating with older people living with Alzheimer's disease and their effects on screaming, even though they are known to be fundamental for creating a healthy environment in LTC homes (Bowers, Fibich, & Jacobson, 2001; Bradshaw, Playford, & Riazi, 2012; Grau, Chandler, & Saunders, 1995; Kitwood, 1993; Kitwood, 1997; Ronch, 2004).

According to Adams and Gardiner (2005), one of the common situations in which communication with people living with Alzheimer's disease occurs is within triads involving a person with Alzheimer's, his family caregiver and a health care professional. This relationship-centered triadic approach takes into account the complexity of the interactions in a clinical setting and the changes in the positioning of each actor vis-à-vis the others (Purves, 2010). The social positions taken by the people in these triads are a relational and social aspect that has not often been taken into account.

Harré and Van Langenhove's (1999a) positioning theory describes a social position as a set of personal characteristics that helps create relational patterns among people that are constantly changing. A social position influences the rights and duties a person perceives to have and the rights and duties that he assigns to the others. For example, a health care professional may position himself as an expert having the right to decide the appropriate time for a treatment and assign the older person with the duty of complying with the care.

Some studies on the social positioning of older people living with Alzheimer's disease have been conducted (Purves, 2010; Sabat, 2002a; Sabat, 2002b; Sabat & Harré, 1992; Sabat &

Harré, 1999). However, they do not provide an understanding of positioning in terms of the specific behavior of screaming, and usually do not consider the triad as an analysis unit. The position of older people within the triad, and the effect of this position on screaming are thereby unknown and very intriguing. Knowledge about this positioning could advance our understanding of the experience and behavior of older people living with Alzheimer's disease, and may offer ways to help provide them with a healthy social environment. In this paper, we will therefore present a study the goal of which was to describe the social positioning of older people living with Alzheimer's disease in LTC homes who scream using Harré and Van Langenhove's positioning theory (1999b).

Theoretical framework: Positioning theory and it's relevance for studying older people living with Alzheimer's disease

Harré and Van Langenhove's (1999b) positioning theory is based on social constructionism and discourse analysis. The concept of positioning is different from the concept of role in that it is a more dynamic representation of social interactions, as roles correspond more to a stable social function in human relations. Harré and Van Langenhove (1999b) present social positioning as the building of a discourse between people that continuously influences relational patterns. During an interaction, a person may take a position or be positioned. Any position taken by a person is relative to that of the others and may be contested. For example, if during an interaction, one person positions himself as having control, he then positions his interlocutor as not having control, and the interlocutor may sometimes contest how he has been positioned in the communication (Harré & Van Langenhove, 1999a). The positions taken in the communication are subject to constant change and may be explicit or tacit for the participants of the social interaction.

More specifically, positioning theory describes three types of positioning, namely first, second and third order positioning. In first order positioning, people situate each other in a social interaction. The positioning is therefore intentional or tacit. Second order positioning may occur when first order positioning is called into question during the communication because one of the people contests how he was positioned by another. It is also possible to question the position a person had in an interaction with another person after the interaction, which is third order positioning. Second order positioning and third order positioning are always intentional; that is to say, they require that the person has a goal in mind that directs his action. These two types of positioning are used to either accept or reject first order positioning. Several types of positioning can therefore coexist in a given social interaction, including triads. These types of positioning are influenced by biography, personal experiences and the powers and the rights perceived by the interlocutors (Harré & Van Langenhove, 1991; Van Langenhove & Harré, 1999). Figure 1 shows the various elements of this theory (see Figure 1).

Choosing to use positioning theory as a framework in a study of older people living with cognitive impairment raises the important question of whether or not they have the capacity to take a position and participate in second and third order positioning. In fact, the capacity to position oneself and others involves willingness to position oneself and the power to do so (Harré & Van Langenhove, 1991; Van Langenhove & Harré, 1999), while older people living with Alzheimer's disease in LTC homes are usually perceived as being powerless and unable to make these types of deliberate actions. Sabat and Harré (1992; 1999) mention that this perception may be due to the willingness of the others to perceive the person in this way and not the actual symptoms of Alzheimer's disease. This notion fits in with the views of Kitwood on malignant social psychology and the fact that older people may, due to this powerlessness, lose hope of

being heard and then use other means to communicate, for example, by screaming (Kitwood, 1993; Kitwood, 1997). This framework was thereby used to help clarify these aspects.

Method

This article presents a secondary analysis of the data from an original study that explored, with the help of older people and their family and formal caregivers, the meanings of screams in older people living with Alzheimer's disease and their influencing factors (Bourbonnais & Ducharme, 2010). The results of this critical ethnographic study showed the social positioning capacity of older people who scream, without deepening the understanding of this phenomenon. By triangulating the data collection methods, this critical ethnography nonetheless provided a quantity and quality of data creating a context conducive to secondary analysis (Åkerström, Jacobsson, & Wästerfors, 2007). This type of analysis is defined as the reanalysis of existing data so as to derive new conclusions about a concept that was found to be important in the original study (Fielding, 2000; Heaton, 1998, 2004; Hinds, Vogel, & Clarke-Steffen, 1997; Rutherford & Parker, 2003; Smith, 2008; Thorne, 1998). This reanalysis may involve a new framework and be conducted by the original researchers (Coltart, Henwood, & Shirani, 2013; Fielding, 2000; Smith, 2008). This is described as being an effective approach for developing knowledge, particularly with respect to phenomena occurring in vulnerable populations, by not having to collect additional data (Corti & Thompson, 2007; Heaton, 1998; Thorne, 1998). Some authors point out that the amount of time elapsed and the familiarity of the researchers with the data facilitate the emergence of new perspectives in the reanalysis (Åkerström, et al., 2007; Coltart, et al., 2013; Heaton, 1998).

Sample

Seven triads, each comprising an older person who screams, a family member and one or two formal caregivers, were recruited for a total of 23 participants. A theoretical sampling strategy was used to select participants while collecting and analyzing data. The purpose of this strategy is to gather knowledge about the phenomenon by comparing the ideas of participants having different characteristics (Agar, 1980; Fetterman, 1998; Mackenzie, 1994). For example, older people expressing different types of screams and caregivers with various cultural backgrounds were included in the sample. The recruitment of the triads stopped once data saturation was reached. The participants came from an urban LTC home affiliated with a university. The older people recruited had to have Alzheimer's disease or a related disorder; manifest vocal behaviors and have a primary family caregiver. The family caregiver was the family member most involved with the older person. The formal caregivers were registered nurses (RNs), licensed practical nurses (LPNs) or nurse's aides (NAs) who knew the older person the best. Authorizations were obtained from the nursing home's management and the Institutional Review Board. All participants signed a consent form approved by the Institutional Review Board. Family members gave consent for the older people living with Alzheimer's.

Data collection

Many data collection tools and methods specific to each group of participants were used to increase the depth of the findings (Boyle, 1994): socio-demographic questionnaires, interviews, observations, informal conversations, field notes and a journal. All the data were considered in the reanalysis, in particular the data from the interviews and observations.

A semi-structured individual interview was done with each family and formal caregiver. The interviews lasted between 30 to 110 minutes with an average of 75 minutes. The shorter

interviews were at the start of the study as less data had to be cross-checked. As family caregivers narrated spontaneously the life story of their relative, these interviews were the longest (over 60 minutes). All interviews were conducted using guides based on Adams and Gardiner's theory (2005). This theory describes communication within the triads as being influenced, among other things, by positioning. For example, questions invited family and formal caregivers to discuss the various positions they took with respect to the older person when he screamed, and those of the other actors. Other questions asked what the participants did when the older person screamed and what they thought could change in their interactions. Despite the desire to conduct interviews with the older people, the legal context in Quebec regarding research on people with cognitive impairment, namely article 21 of the Civil Code (Gouvernement du Québec, 2002), restricts this type of practice. Nonetheless, in order to take into account their experience, observations were made of the older people while they screamed and of the context in which they were screaming. These observations were conducted systematically using a tool based on the empirical literature on screaming and developed specifically for the study. The observations targeted characteristics of screams (e.g., intensity, frequency, type) and of the environment (e.g., level of noise and light). The tool was content-validated by experts in geriatrics.

Data analysis

The reanalysis of the data first involved the rereading of all the verbatim records and the assigning of new codes to all the types of data collected using Harré and Van Langenhove's positioning theory (1999b) (see Figure 1). The coded data were then sifted for similarities and differences so as to identify the positions taken in the triads and any variations observed in these positions. This was done using Spradley's (1979) thematic analysis and by considering the triad as an analysis unit. The last step in the analysis involved verifying the results by comparing new

knowledge with the existing literature. Seven quality criteria guided the reanalysis process to ensure that the results: 1) correspond to the knowledge transmitted by participants (credibility); 2) are grounded in the data (confirmability); 3) take into account what is important for participants (meaning-in-context); 4) identify recurring positioning themes (recurrent patterning); 5), are comprehensive (saturation); 6) are relevant to other contexts (transferability) and 7) take into account inconsistencies in the data (criticality) (Leininger, 1997; Whittemore, Chase, & Mandle, 2001).

Results

The older people who were part of the triads, four women and three men, were on average 81 years old [range: 72 to 94 years]. To be admitted in the long-term care home, the older person needed at least three hours of care per day. This standard is an indicator of cognitive and functional abilities of older people. According to their registered nurses, these participants had moderate to severe symptoms of dementia. The family caregivers of these older people were all women with a mean age of 57 [range: 42 to 72 years]. They visited their loved one at least once a week. Finally, the nine formal caregivers participating in the study, namely six RNs, two LPNs and one NA had a mean age of 48 [range: 38 to 58 years] and 19 years of clinical experience with older people living with Alzheimer's disease [range: 1 to 29 years](for more details, see original study by Bourbonnais & Ducharme, 2010).

Using Harré & Van Langenhove's positioning theory (1999b), the analysis of the data enabled us to identify three themes. Two of the themes describe the positioning from the point of view of the older people, namely how they position themselves in their interactions with others and how they are positioned by family and formal caregivers. The third theme adopts the point of view of family and formal caregivers and describes the positions they take in their relational

patterns with the older person. As positioning is done dynamically and simultaneously among the actors, the themes are intertwined. However, in the interests of clarity, they are presented separately and supported by extracts from the data. All names used are pseudonyms[2].

The older person positions herself in her interactions with her family and formal caregivers

An older person living with Alzheimer's disease who screams is able to position herself in her interactions with her family and formal caregivers. Three sub-themes in our analysis more specifically describe the positioning behavior of older people: 1) the older person positions herself by recognizing her family caregiver; 2) the older person positions herself by trying intensely to communicate with her formal caregivers and others; and 3) the older person repositions herself in her interactions with her family and formal caregivers.

The older person positions herself by recognizing her family caregiver

Despite her cognitive impairment, the older person positions herself differently with her family caregiver than she does with other people. She positions herself as a relative who is happy or reassured to see a loved one rather than positioning herself as a patient. Consequently, the older person can stop screaming when her family caregiver is around, but screams when in contact with the others, thereby directing the dynamics of the communication.

> *When I'm there, she usually doesn't scream. The other day, they were changing her dressing and it was quite painful (…) she tensed up and was scared, but when I was there she didn't scream at all. I was told that she usually screamed [Mrs. Emma's daughter].*

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[2] Given the predominance of women in the sample, the feminine form will be used in the article without prejudice for men.

This change in behavior does not necessarily mean that the older person is able to identify the name of the family caregiver or their relationship. However, the quality of the interaction that ensues is specific, often simply because the older person can see that the family caregiver is there. The older person sometimes even positions herself by explicitly expressing her affection toward the family member. Here's what a family caregiver says about this: *She's already told me that she loved me a lot, very clearly [Mrs. Danielle's daughter].* Other times, the older person will position herself by demanding to be with her family or by not wanting her family caregiver to leave the care setting.

> *He told me that he was very sad because he was here and his daughter didn't come today, but his daughter did in fact come, he had simply forgotten. I said to him, it's almost midnight, she can't be here (...). He didn't seem to accept what I was saying, he thought that his daughter should be here with him (...) two seconds later, he started hitting and swearing [Mr. Francis's formal caregiver].*

Lastly, the older person may take the position of being concerned about the well-being of her family caregiver or in some ways of taking care of her, as seen in the following comments made by the daughter of an older person:

> *He's well aware that it would be very hard for me if he stayed at my place, because he tells me all the time that it's hard for me, that I should take care when I am pushing his wheelchair when we go for walks [Mr. Francis's daughter].*

The older person positions herself by trying intensely to communicate with her formal caregivers and others

Through some of her screaming or by repeating a vocal behavior, the older person is addressing the formal caregivers directly. By means of her behaviors, the older person is

positioning herself as a person whose behaviors are meaning-driven. These meanings can be various unmet needs, emotions or dissatisfactions that are expressed until the formal caregivers respond, namely in their way of being, a specific care or meeting a need.

> *At one point, he was experiencing discomfort, he screamed in the evenings, among other things, because he had wet himself or because the nightlight was turned off. Yeah, when the nightlight is turned off, it happens right away. Turn in on again and quickly he would stop screaming [Mr. Charlie's formal caregiver].*

The older person may also position herself in a dominant manner toward her formal caregivers and others by ordering them around to have them meet her needs:

> *Caregiver: [Sometimes when he screamed], he's not suffering, he's giving orders. Maybe he thinks we're his employees (…). Interviewer: Therefore, if he could explain why he was screaming, what would he say? Caregiver: Giving orders, I'm your boss, do this [Mr. Bernard's formal caregiver].*

This position of the older person seems to be interpreted by the formal caregivers as a symptom of the cognitive impairment instead of a legitimate position considering that she has the needs and rights to be taken care of.

For the family caregiver, the positioning of the older person is consistent with her former means of communication, suggesting that biography and personal experience may be at play in the positioning of the person, even if she is living with moderate or severe symptoms of Alzheimer's disease. Therefore, if the person used to scream often when she was younger, screaming could be a typical reaction for her and not necessarily a symptom of Alzheimer's disease. Mr. Charlie's family caregiver stated that:

> *Before the dementia, he used to scream all the time, because there was a car in his way, because the table was in the wrong place. He was a polite man, well-*

mannered, but when things didn't suit him, he would say so loud and clear. So, [it's

not surprising] to hear him scream now [Mr. Charlie's wife].

The older person repositions herself in her interactions with her family and formal caregivers

The older person seems to be capable of second order positioning, i.e. of contesting the position assigned to her by her family or formal caregiver. This ability is demonstrated, for example, when the family and formal caregivers are talking without including the older person in the conversation. In some cases, when excluded from the interaction, the person will reposition herself by intervening in the conversation or by becoming more agitated, and will then calm down when allowed to take part in the discussion or when one of the members of the triad leaves:

Daughter: The other day, the last time she was with the doctor, she was frustrated,

she didn't like it and told him to "get out of here" or something to that effect, she

told the doctor to "go" (laughter) (...). Interviewer: So, what happens when you

interact with other people? Daughter: She doesn't like it (...), but it does not bother

her if it only lasts for a few seconds or minutes, but it should be quick. She doesn't

like it at all [Mrs. Emma's daughter].

By not including the older person in the conversation, she is being positioned as unable to participate and unlikely to object to this position. The contestation of this position by the older person can therefore be seen as a healthy reaction when being treated impolitely instead of a pathological response or a form of agitation.

In addition, the older person positions herself differently depending on the relation with the formal caregiver. This relation is influenced by the way the older person is positioned by the formal caregiver. With some formal caregivers, the older person will reposition herself and will

cooperate or stop screaming, while with others, the screaming will continue, demonstrating a different dynamic depending on who she is interacting with. The following nurse's comment is an illustration of this dynamic.

> *The companion who was always in her room said, my goodness when you show up,*
>
> *she's not the same (...). Sometimes, she wouldn't eat all day if I wasn't there. I*
>
> *would come in and she ate everything and she laughed, smiled. She always*
>
> *answered me. [Mrs. Anna's formal caregiver]*

In other words, older people living with Alzheimer's disease who scream are capable of positioning themselves in order to modulate the direction and quality of the relational patterns, which is influenced by how they are positioned by the others.

The older person is positioned by her family and formal caregivers in her interactions

Given the cognitive impairment of older people, it is difficult for family and formal caregivers to know exactly what older people living with Alzheimer's are going through and what they want. During interactions, family and formal caregivers therefore position the person based on what they believe she is experiencing. These beliefs are based on their knowledge of the older person's biography and an analysis of her reactions in the context of the care setting.

The family caregiver relies on her beliefs, including the possible preferences of her older relative, her needs and the emotions she is currently experiencing in the LTC home, which influence the positioning. Some examples of beliefs relating to preferences are that the older person prefers a gentle approach, that she would like her loved ones to stay longer or that she would prefer going for a walk with her family.

> *I think that what she's probably saying is that she'd like me to stay longer, even if*
>
> *I'm not sure she's always aware that I'm there (...), but what is this [screaming]*

about, what could be wrong? Perhaps she wants me to stay longer [Mrs. Danielle's

daughter].

Very often, the family caregiver will explain that the older person is screaming because her preferences are not being respected. This inference about the older person's behavior positions her as an actor using her screaming to communicate with the others. The family caregiver also has beliefs on the needs behind the screaming, such as a physical need or the need for pain relief. She attributes several emotions to the older person, for example, fear, anxiety or frustration. These beliefs influence how she communicates with the older person.

I am certain that when they lift her, when they do anything, it's painful, she bruises

easily, it has to really hurt, she has some arthritis and I'm convinced this is why she

screams [Mrs. Emma's daughter].

When the family caregiver shares these beliefs, she can also influence the way formal caregivers position the older person.

Formal caregivers also have beliefs that come into play in how they position the older person, although they do not express as many beliefs as family caregivers. The beliefs they expressed were also mentioned by the family caregivers. For example, both family and formal caregivers believe that: the older person who screams is experiencing pain; she is perceiving the care to be an assault; she is experiencing psychological distress; she doesn't want to be treated like a thing and only be touched when receiving care.

When it's supper and care time, when we transfer him from his chair to his bed

[...], he starts screaming and hitting when he's being moved, and he wonders "what

do they want, what do they want me to do, why are they doing this, why are they so

short with me, why are they moving me?" [He feels] assaulted [Mr. Francis's

formal caregiver].

In short, the older person's cognitive impairment leads family and formal caregivers to speculate about the possible meanings behind the screaming and, based on their beliefs, lets them position the older person in her relational patterns. As previously mentioned, the older person may accept or contest the position assigned in this context (second order positioning).

The family and formal caregivers position themselves in their interactions with the older person

The position that the older person takes or the position that is assigned to her determines the position of the family and formal caregivers in their interactions. Two sub-themes of our secondary analysis describe the manifestation of this positioning, i.e.: 1) their reactions toward the older person; and 2) their attempt to influence her. In many ways, the family and formal caregivers are similar, but they sometimes take different positions. The results are therefore presented for both groups by emphasizing the differences.

Reactions toward the older person who screams

The family caregiver may position herself based on her emotional reactions in her interactions with an older person and the formal caregivers. In some cases, the family caregiver positions herself as being ashamed of her loved one who screams or as feeling guilty for not visiting her enough: *I witnessed her screaming a few times, and it sounds crazy, I mean, if there were people around that I didn't know, I'd be a bit ashamed [Mrs. Gisele's daughter].*

The family caregiver also reports positioning herself as being powerless over the situation. The following excerpt demonstrates the position of a family caregiver:

> *I feel powerless. I don't like seeing her like that because she really seems unhappy*
>
> *when she does that [screams]. And I feel powerless. A feeling of powerlessness (…)*

because I try the little things I do or say and it doesn't work at the time, because it

doesn't always work [Mrs. Danielle's daughter].

Formal caregivers also report these feelings of guilt, of not having enough time to spend

with the older person, and of powerlessness about the screaming. The following excerpt

highlights the similar position of a formal caregiver:

You ask yourself why [he screams], you know, it's like powerlessness, too. But why

doesn't he stop, you know, why is he doing this? I want him to stop, he says he will

and then keeps screaming; to some degree, it's offensive, frustrating and baffling

[Mr. Charlie's formal caregiver].

The family caregiver reacts by wondering why the older person screams, as do the formal

caregivers who say they are confused by and concerned about the screaming.

We're wondering what happened all of a sudden? The first time we heard it, we

said, what's going on! We went into the room, examined everything, does he need

changing? Is he hurting? No, his eyes are closed and he's screaming like that. As I

was saying, there are five reasons [for screaming] that I've discovered, but this

screaming, it was really like what's going on [Mr. Charlie's formal caregiver].

Family and formal caregivers are therefore positioning themselves as unsure of the meanings of

screams. As a consequence, they use a trial-and-error approach with the older person to influence

the screams.

Attempts to influence an older person who screams

Several different strategies are used to influence the older person. Sometimes the family

caregiver positions herself as being in charge of the older person. She therefore asks her to stop

screaming or tells her that she will handle making the decisions.

I told her to stop screaming, I believe that it's my role. I know that I can help her

with this (...) I don't let her do it, and she stops [screaming] [Mrs. Danielle's

daughter].

The older person may accept this position and stop screaming or appear to be relieved, as she no longer has to worry about a problem. However, the family caregiver may not enjoy this position of authority. She has a tendency to alternate between a more parental-type position and that of being the child of the parent:

Daughter: I'm in charge and I accept it. I don't want to say that's what he wants but

he accepts it willingly (...). He wants me to be in charge (...) and help with

everything, yes, I control everything and he prefers it like that. But not all the time,

sometimes I'm the daughter (...), when he's doing well, I tell him my problems; I

kiss him like a daughter, although most of the time I kiss him as a person in charge

(...). Like now, I'm at his side, at his bedside, I give him a banana, I tell him things,

I kiss his hand, it's as if I'm his little girl and he likes it a lot and I tell him about the

problem I'm having with my car [Mr. Francis's daughter].

Despite an organizational culture that sometimes prompts formal caregivers to be prescriptive toward older people, they state that they avoid positioning themselves to be in charge when an older person is screaming, as it seems to heighten the screaming. They position themselves rather as explorers of the underlying causes of the screaming by asking questions to the older person. In other words, the older person seems to react differently to the same positioning depending on which actor is holding the position of authority. More specifically, with a family member, the older person very often stops screaming, while this same position held by a formal caregiver can have the opposite effect.

Both family and formal caregivers take up a protective and reassuring position toward the older person in order to reduce the screaming. They try to adjust to her abilities and comfort her. The family and formal caregivers show these positions through their actions, for example, by touching the older person, by bringing her food or things she likes. They also try to do so by talking to her.

The other day, she was given some applesauce to eat (…). I said, mom, you don't seem to like this sauce. She said no! (…) She prefers ice cream. So, I obviously tried to make her as comfortable as possible [by bringing her ice cream] [Mr. Danielle's daughter].

Both groups will also try and directly influence the screaming by asking the older person to stop screaming or by asking her why she is screaming. In some cases, the family caregiver is surprised when the older person manifests second order positioning by saying that she is not screaming. In other cases, the older person positions herself explicitly as not being able to stop.

When he screams, he'll give you some kind of reason, but he stops [screaming]. I'm used to this, I arrive while he's screaming and he's swearing and I hear him through the door and I go in. He sees me and I tell him that I heard some terrible things, why do you do that and he tells me that it wasn't him [Mr. Francis's daughter].

In summary, the family and formal caregivers position themselves in various ways in their relational patterns with an older person who screams. The recurring positions seem to be the ones having the most impact on the older person's screaming. This reflects the dynamics within the triad and the capacity of the older person to position or reposition herself toward the others, even if it's only through her behavior. Our results

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therefore indicate that the older person is participating in these dynamic interactions, that she tries to influence the others within their micro society (the LTC home), and that despite the unusual methods used, such as screaming, she succeeds in transforming the interactions.

Discussion

The goal of this secondary analysis was to describe the social positioning in LTC homes of older people living with Alzheimer's disease who scream using Harré & Van Langenhove's positioning theory (1999b). The results show that older people who scream take various positions within the triad. They are also positioned in their interactions by the beliefs held by their family and formal caregivers based on their experience in the LTC home. These beliefs appear to be significant, as it is difficult for the actors to validate their views directly with the older person who has a cognitive impairment.

Our analysis also indicates that the positioning of the members of the triad was not solely expressed through languaging, but also through verbal and non-verbal behavior. It highlights that older people seem to be capable of second order positioning, which, according to Harré & Van Langenhove (1999b), involves questioning the first order positioning. This questioning is expressed more through starting or stopping to scream during interactions than through explicit self-affirmation.

In view of this limited explicit self-affirmation, it is difficult to identify third order positioning in older people who scream, that is observing their acceptance or rejection of first order positioning once the initial interaction is over, for example, a few hours or days later (Harré & Van Langenhove, 1999b). In fact, since third order positioning is not expressed right away, it is difficult to associate with certainty a tacit behavior with a delayed repositioning. It is also

difficult to know whether the memory abilities of the older person suffering from severe cognitive impairment allows her to consciously re-examine a position imposed by a family or formal caregiver during a previous interaction.

Positioning theory (Harré & Van Langenhove, 1999b) states that positioning may be tacit or intentional. As described earlier, first order positioning is mainly tacit, while second and third order positioning is always intentional. Based on this theory, the signs of second order positioning in older people living with Alzheimer's disease would indicate they are capable of intentionally influencing the relational patterns, at least in the immediate term. As previously mentioned, this theory states that an intentional positioning requires the person to have a goal in mind that directs her action. This notion is coherent with the concept of intentionality that can be defined as the characteristic of actions committed deliberately (Malle, Moses, & Baldwin, 2001; Reuter, 1999). Case studies have demonstrated these capacities in some people with Alzheimer's disease (Sabat, 2000, 2001; Sabat & Harré, 1994). Nevertheless, as the specific effects of Alzheimer's disease on consciousness and self-awareness are not currently clear, it is often difficult to explain how persons suffering from severe cognitive disorders express intentionality (Caddell & Clare, 2011). Based on a synthesis of neurocognitive models of behavior by Brown and Pluck (2000), a purposeful behavior is driven by intention, even if the person is not aware of a goal or desire in the context where the behavior is associated with an event in the environment or a repetitive situation. Intentionality in the positioning of older people living with Alzheimer's disease who scream fits in with the notion of the pre-reflective body described by Merleau-Ponty. The pre-reflective body means that the body is in relation with the environment and is a place of physical and sensory experience leading to intentional actions, without a person being necessarily aware of how she is guiding her actions (Kontos, 2005; Merleau-Ponty, 1962). In summary, both neurocognitive and philosophical literature define intentionality to be inclusive of older people

living with Alzheimer's disease, which supports the signs of intentionality identified in our results.

The results also showed that family caregivers rely on the life history of the older person. The positioning of the older person is thereby interpreted as being in continuity with their previous life. This manner of identifying the positioning corresponds to some of the elements described by Harré & Van Langenhove (1999b), namely biography and personal experience. These authors also mention power and the right of exercising it as an element that explains behavior.

Even if power can be defined in various ways, for example, hierarchically by making reference to the fact of having power over something or someone, or as being the fact of having the ability to free oneself from oppression (Polifroni, 2010), Foucault's conception of power is the most useful in analyzing positioning within a triad involving an older person living with Alzheimer's disease. For this philosopher, power is a right and is ubiquitous. It thereby concerns any human being, regardless of her abilities or her role, and does not depend on the level of awareness. Foucault (1976) stated that power "is the name we give to a complex strategic situation in a particular society" (p. 123, own translation). In this perspective, power is a dynamic social phenomenon rooted in relationships (Foucault, 1980; Kuokkanen & Leino-Kilpi, 2000; Lawrence, 1988) that corresponds well to the postulates of Harré & Van Langenhove's positioning theory (1999b). It also applies to care triads involving an older person living with Alzheimer's disease who screams. This notion of power is of particular interest but rarely addressed in long-term care, especially the notion of power and rights of older people living with Alzheimer's disease. Our results provide a better understanding of how the element of power described in positioning theory can be applied to explain the behaviors of older people who scream, and those of their family and formal caregivers. This concept of power enables us to

view power among the members of the triad in a more egalitarian manner, as each member may try to transform dynamically the relational patterns.

This egalitarian goal is coherent with the results of the study, for instance the attempts of family caregivers to allow the older person to take part in decisions or to give advice, which often puts an end to the screaming. Formal caregivers also try not to be authoritarian and to establish more friendly relations. This reciprocity brings about a better physical and emotional adjustment of the older person (Nelson, 2000). The results of our secondary analysis seem to show that older people are capable of reciprocity although, as indicated by Graham, Eustace, Brock, Swain, and Irwin-Carruthers (2009), they might have difficulty articulating their need for a more egalitarian interaction. For instance, though they might want to help a caregiver with a task or negotiate another time for a specific care, they might not be understood. Even if older people living with Alzheimer's disease remain aware of their interactions (Graham & Bassett, 2006), the responsibility for decoding the positioning and establishing this reciprocity seems to lie with family and formal caregivers.

According to Nelson (2000), however, this reciprocity is very often perceived to be impossible due to physical and cognitive impairments, low expectations of others in view of these impairments or the use of coercive authority. These perceptions position the older person with Alzheimer's disease as a dysfunctional person, thus disempowering her. This probably explains why the care is often provided unidirectionally to this clientele (Graham & Bassett, 2006), i.e. that formal caregivers tend to make all the care decisions without the older person being able to participate as a partner in this care or having the chance to do something in return.

This study describes positioning using the case of older people living with Alzheimer's disease who scream, but certain limitations may have influenced the results. First, as this was a secondary analysis, we were unable to collect additional data in order to have a better

understanding of the dynamic positioning taking place in the triads. Another limitation is that the data on the positioning of older people come from the perceptions of family and formal caregivers. These actors had to infer the experience of the older person. Triangulation among the actors and among data collection methods nonetheless ensures the credibility of the results. Furthermore, the quality criteria yielded results that: are grounded in the data, consider the context of the participants, refer to recurring themes and take into account the discrepancies in the data. Moreover, even if our results are specific to the case of older people who scream, they may provide a better understanding of the social positioning of older people living with Alzheimer's disease, whether they scream or not, ensuring the transferability of the results.

Although Harré and Van Langenhove's positioning theory (1999b) was relevant as a framework to understand better the positioning of older people in LTC homes, some elements of this theory made its application to the case of older people living with severe Alzheimer's disease more difficult. The applicability of the theory would be facilitated through clarification of certain concepts, especially the concept of intentionality that is only described in terms of type of positioning intention and the concept of power, which is not explicitly defined.

Based on our findings, some recommendations can be made that could improve the quality of care for older people living with Alzheimer's disease at a severe stage. The capacities of these older people have been studied (Clare, 2010; Clare, Rowlands, Bruce, Surr, & Downs, 2008; Hubbard, Tester, & Downs, 2003). However, more knowledge is needed about the capacities of these older people, notably about their consciousness, self-awareness or intentionality. Interdisciplinary studies (e.g., sociology, neuropsychology) should be conducted to understand these capacities and to target interventions accordingly. These developments would provide knowledge on preventing the deterioration of capacities and optimize the well-being of these older people.

Moreover, given the positioning capacity of older people in their relational patterns with family and formal caregivers, these two groups of actors should be encouraged to consider the behavior of older people, for example, screaming, aggression, walking, not only as symptoms of a pathology, but rather as having meaning and manifesting a dynamic social position. As older people living with Alzheimer's disease appear to be limited in initiating reciprocity gestures that have a positive effect on their behavior, activities that allow this reciprocal relationship should be promoted. In fact, our results show the importance of relationships within LTC homes, both for older people and for their family and formal caregivers. Moreover, according to Anderson et al. (2005), changes in LTC homes and improvements in care stem from the quality of the relationships among the members of the triad. Lastly, transforming the care so that it be individualized and focused on the abilities of older people rather than solely on their impairments, requires promoting the empowerment of family and formal caregivers. With structural equation modeling, Caspar and O'Rourke (2008) showed that 50% of the ability to provide individualized care by formal caregivers is explained through structural empowerment, i.e. the informal and formal power they have in the facility, the information to which they have access, the resources available and the opportunities to face new challenges at work. The management philosophy in the LTC home thereby has an impact on the positioning within the triads.

In conclusion, the use of positioning theory offers a different perspective on older people living with Alzheimer's disease who scream. It highlights their strengths and potential, as well as the family and formal caregivers concerns to understand them. It also shows the dynamic nature of relational patterns and the ability of older people to influence them. Despite having different experience, older people, family caregivers and formal caregivers seem to share several similarities, thus revealing universal features that unite them. The acknowledgement of this

universality is fully conducive to the development of compassion and empathy, attitudes that promote a caring environment for each member of the triad.

Note

Extracts from the data were originally in French. They were translated for the purpose of this article.

Acknowledgments

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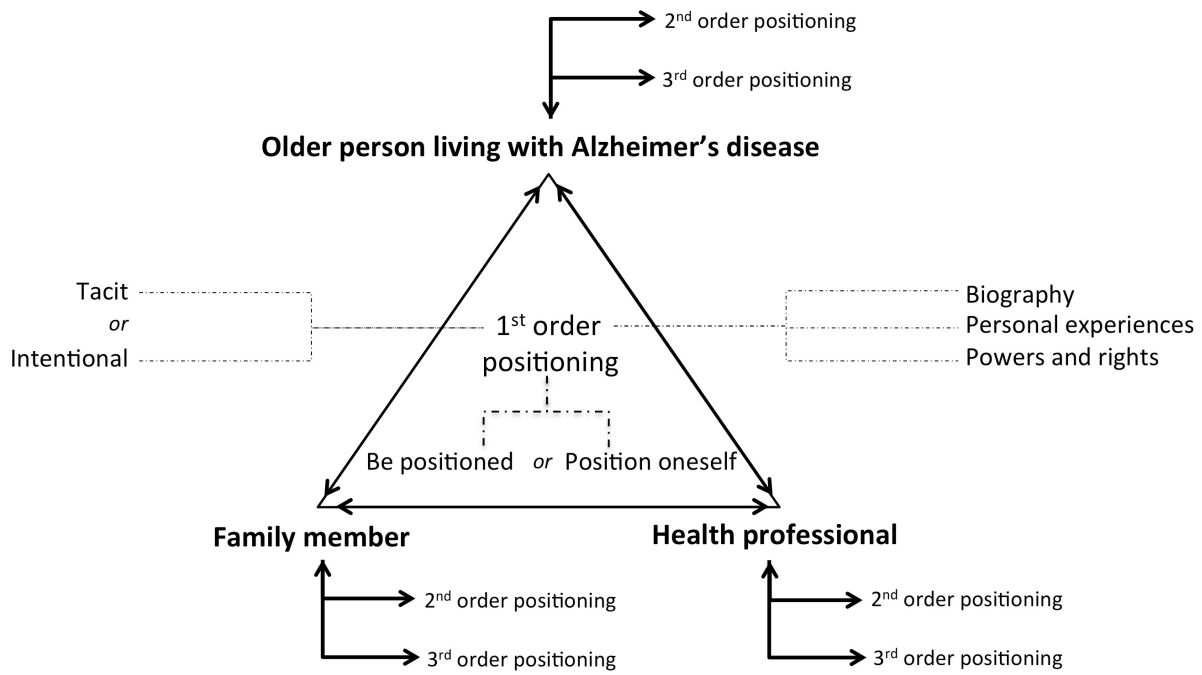
Figure 1. Representation of the positioning theory with a triad (inspired by Harré and Van Langenhove, 1991).