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# Behavioural changes in dementia and their impact on professional caregivers: A grounded theory approach

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## Abstract

**Aim:** The present study aimed to explore the impact that changes in behavioural symptoms of people living with dementia have on professional caregiver and resident relationships.

**Method:** A total of 21 interviews were carried out with professional caregivers of people living with dementia. A grounded theory approach was used to investigate everyday experiences of provision of professional care in dementia settings, focussing specifically on the effect of behavioural change on such relationships.

**Results:** A core category emerged from this analysis: 'Developing behaviour in dementia impacts relationships on a personal and professional level'.

**Discussion:** Professionals have recognized as part of their everyday practice an eventual deterioration in relationships between themselves as professional caregivers and the residents, but also between the residents and their family members and among residents themselves. Importantly, understanding patients' behaviour and behavioural change was identified as a crucial factor to achieve and sustain good relationships between professionals and residents suffering with dementia.

## Keywords

grounded theory, dementia, caregiver–resident relationships, behavioural changes

## Background

As life expectancy rises, so does the worldwide incidence of dementia. Today, more than 46 million people live with dementia. This number is estimated to increase to 115.4 million by 2050 (Prince et al., 2013). Unsurprisingly, dementia has become an area of growing concern, with governments aiming to put in place strategies to reduce risk factors, investing on early intervention and on the provision of the best possible care for sufferers (Prince et al., 2013). The main focus of research concerning the provision of care is, however, considerably centred on people with mild to moderate dementia who currently still reside in the community. This extensive research tails off dramatically as the dementia becomes more severe and individuals move into residential or nursing homes (Clare, Rowlands, Bruce, Surr, & Downs, 2008). However, it is not uncommon for dementia sufferers to need some form of regular professional care in residential or nursing home settings with an accompanying incremental need for specialized professional care staff. Importantly, those residing in such care settings tend to display a higher level of dependency and behavioural change with staff more likely exposed to challenging behaviours such as agitation, motor-disturbance, night–time behaviour and changes in eating behaviour (Risco et al., 2015). Yet, very little research is dedicated to the understanding of this complex interactional context. This study sought to address this gap in previous research by shedding a light on the experience of caring for people living with dementia in a professional capacity.

Individuals living with dementia, especially in more advanced stages, might display a plethora of behavioural changes which often involve dramatic fluctuations in sleeping patterns, eating behaviour, mood, sexual behaviour, aggression propensity, interpersonal skills, self-care and temperament (Hayward, Robertson, & Knight, 2012; Hooren & Waterink, 2015; Ikeda, Brown, Holland, Fukuhara, & Hodges, 2002; Mioshi et al., 2013). Furthermore, other behaviours might emerge as dementia progresses: delusions, agitation, depression, anxiety, indifference and aberrant motor behaviour (Pieper et al., 2013).

Witnessing these changes might have a strong impact not only on families and friends, but also on professional caregivers. Nevertheless, despite the body of research dedicated to the exploration of the impact of such changes on family and friend caregivers (cf. Jensen, Agbata, Canavan, & McCarthy, 2015; Park & Park, 2015) considerably less is known about the experience of professional caregivers (Ducharme, Kergoat, Pascal, Pasquier, & Coulombe, 2014).

It is therefore our aim to address this underexplored yet undeniably relevant issue by adopting a qualitative method which will allow a deep and rich characterization of the context of interest. Our main focus will be to understand the factors that can affect the quality of the relationship between the person living with dementia and the professional caregiver as the quality of this relationship is often identified as one of the most influential factors for caregiving satisfaction (Quinn, Clare, McGuinness, & Woods, 2012).

Interestingly, closeness and loss of closeness between family caregivers and the care recipients, has been associated with both positive and adverse outcomes. In fact, a closer relationship between caregivers and care recipients has evident positive outcomes for the care recipients (Fauth et al., 2012). In reference to change in relationship with family members and spouses, research has discussed the ‘deprivation of intimate exchange’ as well as the components of a strong relationship including love, respect, trust, appreciation and the quality of interaction. The development of dementia has a large impact on the care recipient’s ability to express any of these components and the behaviours they display can

appear to exhibit the opposite values (Fauth et al., 2012). A greater understanding of the dementia diagnosed in a spouse naturally leads to better adjustment and emotional responses (Stokes, Combes, & Stokes, 2014) inevitably affecting this relationship.

Poor attachment styles between health care professionals and patients suffering with dementia have been related to higher levels of staff burnout (Kokkonen, Cheston, Dallos, & Smart, 2014). Burnout has a negative impact on staff behaviour which might lead to lower levels of empathy and less willingness to help (Brooker & Latham, 2015). Challenging behaviour plays a key part in burnout and job satisfaction of individuals who are caring for dementia (Zwijnen et al., 2014) changing the nature of relationships between residents and professional caregivers. This may be a temporary or permanent change which may in turn affect their care.

Importantly, high-quality relationships with the patient decrease the level of caregiver burden and subsequent anxiety and depression levels which are determined by behavioural disturbances (Hall et al., 2014; van der Lee, Bakker, Duivendoorn, & Drbes, 2014). These findings highlight the importance of investigating the relationships between dementia sufferers and those surrounding them and caring for them.

Several areas of empirical research have identified the struggle of spousal caregivers when their loved one becomes a resident in a care facility. Typically, caregivers find it changes their relationship (Ritchie & Lovestone, 2002) and as such, they struggle to grasp what they should and should not be doing for their loved one anymore. Spouses often feel 'They aren't really yours anymore'. a feeling which is accompanied by a loss of identification with the individual (Hemingway, MacCourt, Pierce, & Strudsholm, 2014, p. 7). Furthermore, a lack of engagement received can sometimes hurt their family or spousal relationships and may lead to a lack of willingness to visit the patient, expressed by sentences such as 'Then when I get there and he's, you know, no response I think why have I come?' (Hennings, Froggatt, & Payne, 2013, p. 687). Little research has investigated the impact of individuals' understanding of dementia on the provision of care a resident receives. van der Steen, Onwuteaka-Philipsen, Knol, Ribbe, and Deliens (2013) studied caregivers' understanding of dementia and whether it could be used to predict patients' comfort at death. They used observational methods to do so over a number of nursing homes in the Netherlands. Both physicians and family members were assessed in terms of family decision making and the quality of care provided according to their understanding. It was found that a better understanding of dementia predicted better comfort of care during the dying process. Family would make more suitable decisions and professionals provided a better quality of care. Clare et al. (2008) explain how care staff's understanding of retained awareness in their residents, may assist them in responding to residents needs effectively – which could have an impact on the quality of relationship. Failure of both care staff and family understanding of dementia can result in negative impacts on the development of informed advanced care plans and can contribute to inadequate symptom management (Robinson et al., 2014).

Hence, the current study aims to investigate the impact that developing behaviours have on the relationships that professional caregivers maintain with residents living with dementia. Furthermore, the contributing factors that lead to relationship changes in such contexts will be explored, clarifying the processes that lead to the maintenance of such relationships. The ultimate goal of this research is therefore to provide a better understanding of the experience of caring, in a professional capacity, for people living with dementia. It is expected that the adoption of a grounded theory approach will constitute the most appropriate methodology to explore this topic as this constitutes a virtually unaddressed thematic across the current literature. This methodological approach is ideal for exploring integral

social relationships in settings such as this where there has been little exploration of the contextual factors that affect the interactions of interest (Crooks, 2001) where it is essential to 'get though and beyond conjecture and preconception to exactly the underlying processes of what is going on, so that professionals can intervene with confidence to help resolve the participant's main concerns' (Glaser, 1998, p. 5).

## Method

### *Participants*

Theoretical and convenience sampling was used in this study as it involved participants who were representative of the criteria specified. The inclusion criteria were being employed as a professional health caregiver, working directly with people living with dementia for at least six months. The exclusion criteria were being under the age of 18, having a typical work pattern of fewer than 20 hours per week working as a professional health caregiver.

A total of 21 professional health caregivers were recruited to participate in this study from three different residential and nursing homes located across Hampshire and Sussex including one participant who was a peripatetic care worker, working within differing residential care homes across Hampshire and Berkshire. This sample size was theoretically oriented. The recruitment of participants continued until theoretical saturation was reached. Data collected were analysed until the emergence of fully developed categories, and dimensions of the proposed topic of research interest: the impact that changes in behavioural symptoms of people living with dementia have on professional caregiver and resident relationships. Recruitment was ended once the theorization of the events under investigation was considered to have come to a sufficiently comprehensive end (cf. Charmaz, 2014). Of these 21 participants, two were male and the remaining were female with a mean age of 38 years (range 21–69).

Participants were recruited through direct contact with the managers of the homes via email, telephone calls and face to face meetings. Two of the three homes allowed the interviews to be conducted within the work setting and within work hours and the final home asked for them to be conducted outside of work hours. The latter were therefore conducted within the participant's homes in order to ensure the continuity of a familiar setting.

### *Design*

The focal goal of this research was to provide a greater understanding of the underexplored experience of caring, in a professional capacity, for people living with dementia.

Given the extreme scarcity of current literature approaching this thematic, a grounded theory methodological approach was deemed the most suitable as it would facilitate the investigation of integral social relationships in context where there has been little exploration of the specific factors that affect the interactions of interest, such as this one (Crooks, 2001).

As such, a grounded theory research design was employed. This approach has enabled the exploration of everyday experiences of provision of professional care in dementia settings, focussing specifically on the effect of behavioural change on such relationships with the aim of learning about individuals' perceptions, to focus on their everyday life and to enquire as an interactive, relying on the participants' words.

## *Procedure*

Participants completed a pre-screening questionnaire designed to assess inclusion criteria. This was followed by the main interview which was audio-recorded. Interview length ranged from 6 to 21 minutes. A semi-structured interview guide was used to enable the researcher to adapt the interview in accordance to the responses of the participants. The interviewee lead the interview in a direction they felt appropriate according to the questions and various prompts used in order to help gain in-depth information. The researcher would ask the participants about their general experiences as a professional caregiver and subsequently as a caregiver for someone who lives with dementia. The interviewer went on to cover behaviour seen in their residents and the relationships their residents had with others as well as with the carer themselves.

The interviews ended when there was no novel data emerging that was of relevance to the present study thus achieving 'Theoretical Saturation' (Charmaz, 2014).

The interviews were subsequently transcribed. Analysis of the data was on-going whilst interviews were still being carried out in order to feedback any emergent themes into the data collection that was still being carried out.

## *Data analysis*

A grounded theory approach to this topic was adopted which entailed a simultaneous process of data collection and data analysis with the possibility of an adaptation of the interview strategy. Importantly, once the first five interviews had undergone the first stage of analysis, it came to light that relationship changes were not only apparent in the case of the professional caregivers as primarily being investigated but also with family members and between residents. As a result, the subsequent interviews were adapted to further investigate this.

The first process of analysis performed on the interviews was open coding. At this stage, after several careful readings of each interview, the creation of tentative labels for chunks of data that summarized the main emerging concepts was attempted. Codes were then attached to individual words or phrases that the participants responded with. This was followed by selective coding on multiple lines or phrases and subsequently axial coding where links between categories and subcategories that had been previously formed were identified.

Intercoder reliability of the analysis of the interviews was assessed with the help of an independent coder who analysed randomly selected sections of interviews. The coder was familiar with the field of professional caregiving in dementia but did not have a specific knowledge nor was involved in the present research. Overall, intercoder agreement was established through the coding of various randomly selected sections of interviews that represented 20% of the total data collected. Intercoder reliability of the analysis was calculated using percent agreement and disagreement and agreement was consistently high across the different sections amounting to a total of 80% of agreement.

## **Results**

### *The sub-core categories*

Table 1 presents the different sub-core categories identified across this study.

Table 1. Sub-core categories.

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<i>Displaying negative behaviour (Stage One)</i>	Residents engaging in challenging behaviours and habits.
<i>Understanding of the behaviour (Stage Two)</i>	How well carers, family and other residents understand the behaviour and dementia.
<i>Negative Relationship Change (Stage Three)</i>	Becoming more distant from the resident, bad feeling and not wanting to be around them. Loss of engagement.
<i>Positive Relationship Change (Stage Three)</i>	Building rapport, trust and an understanding of their habits and behaviour with time. Better engagement.

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### *Displaying negative behaviour*

This sub-core variable was displayed across all of the interviews that took place. Aggression, lack of engagement, disrupted sleeping and eating patterns as well as mood swings were highlighted as negative forms of behaviours. Participants made clear reference to the unpredictability of these behaviours and the only clear, consistent trigger for agitation of the residents appeared to be personal care. In what concerns their personal experiences, care-givers described their job as: ‘challenging’, ‘hard’, ‘difficult’, ‘rewarding’ and ‘draining’ (emotionally and physically). When questioned about the reasons behind this, particularly in the context of caring for people living with dementia, the behaviour of the resident frequently arose as a motive.

### *Understanding behaviour*

Some caregivers perceived patients’ behaviour as having some form of direct impact on the way they felt, stating, for example, ‘to start with I felt scared’. Many mentioned understanding that this behaviour was not directly imputed to the personality of the individual and instead was attributable to the developmental process of dementia. This was expressed using phrases such as; ‘I know they don’t mean the things they do’ and ‘our relationship remained consistent because I understand’. However, not all the interviewees were of this opinion, stating an opposite view: ‘Yeah I think their behaviour affects our relationship.. .she knows what she is doing she knows she is winding you up.. .she constantly buzzes’. It would not be unreasonable to suggest that this participant might not entirely understand the condition or the reason behind the behaviour being displayed, simply stating that the resident wishes to ‘wind them up’. This belief may well be hindering the professional relationship between caregiver and patient, consequently having some form of impact on the care provided.

Interestingly, some caregivers also noted a lack of understanding between residents when specific behaviours were displayed. Patients who presented different stages of neurocognitive degeneration would not always be sympathetic regarding display of particular behaviours by other residents. For example, a participant reported that when some residents engaged in behaviours which involved playing with their food, other residents manifested anguish. In one instance, a participant described the change between residents as ‘shunning’ one another in response to negative behaviour. During another interview, a participant explained that some residents begin to ‘eat with their hands’ during the later stages of dementia and they

found that other residents would find this ‘distressing.. .because they don’t understand and just view it as socially inappropriate’ as they are still in earlier stages of their dementia.

Furthermore, some professional caregivers have also noted an impact of particular behaviours on the family of the residents. Participants are of the opinion that families are often shocked at the behaviour their mother/father or spouse was displaying. When noticing this, most seem to be in agreement that relatives often find that it is hard to understand the impact that dementia might have on the individual and struggled to understand the occurrence of behaviours which might be associated with the neurodegenerative condition.

In fact, some participants discussed how family members might sometimes expect too much from their relatives and subsequently become upset or frustrated when patients are unable to meet their expectations. For example, one interviewee explains ‘She would push her too hard and expect too much because she didn’t understand.. .this resulted in the mother almost hating her’.

### *The relationship change (positive/negative)*

Several interviewees have expressed the existence of a learning process which entailed ‘learning how to deal with their residents’, learning their likes and dislikes and the best ways to communicate with them. Interviewees often emphasize the importance of understanding behaviours to maintain a good relationship stating that ‘the more you work with that person.. .you become closer and understand better’. Often participants stated feeling that they have got closer with the residents over time. One, in particular, mentioned ‘It has got easier to recognise wants and needs and it has improved the relationship over time’.

Interestingly, the same interviewee goes on to say that in the context of another resident the relationship has got harder as time goes on ‘.. .she gets annoying when you work with her all of the time’. Another participant discusses a positive change in relationship in what concerns the level of trust and mutual understanding between caregiver and resident. Yet, this does not seem to be transversal as, in what regards another patient, the same caregiver expressed feeling that the relationship had declined with the progression of the dementia.

Figure 1 aims to illustrate the development of data analysis and to clarify the development of the theoretical codes, by representing open codes, central codes, and theoretical codes derived from self-report interview data using grounded theory methodology.

Negative relationship changes appeared to be associated with frustration and sadness with the decline and negative behaviours experienced. In one example, a participant explains that the behaviour makes them feel ‘sad because we can see the dementia is moving forward’ and that, ‘it upsets me to think someone has got to that stage’. When discussing dealing with challenging behaviour, a participant describes feeling ‘both mad and frustrated’. Various further interviewees discuss the frustration of their residents – ‘they can become quite aggressive.. .I think it can quite often be frustration’. Professional health caregivers found themselves not always wanting to be around certain individuals who ‘grated’ on them after extended periods of time. Some participants referred to a lack of engagement for example ‘.. .her eyes will wander – she doesn’t engage anymore’. Some negative behaviours are reported to have a temporary negative impact – ‘in that moment I don’t want to be near that resident if they are being aggressive or whatever towards me’.

A clear theme running through the majority of interviews was the negative impact on resident and family relationships from the perception of the carer. A few of the interviewees highlighted that residents would simply seem unengaged when family members visited.

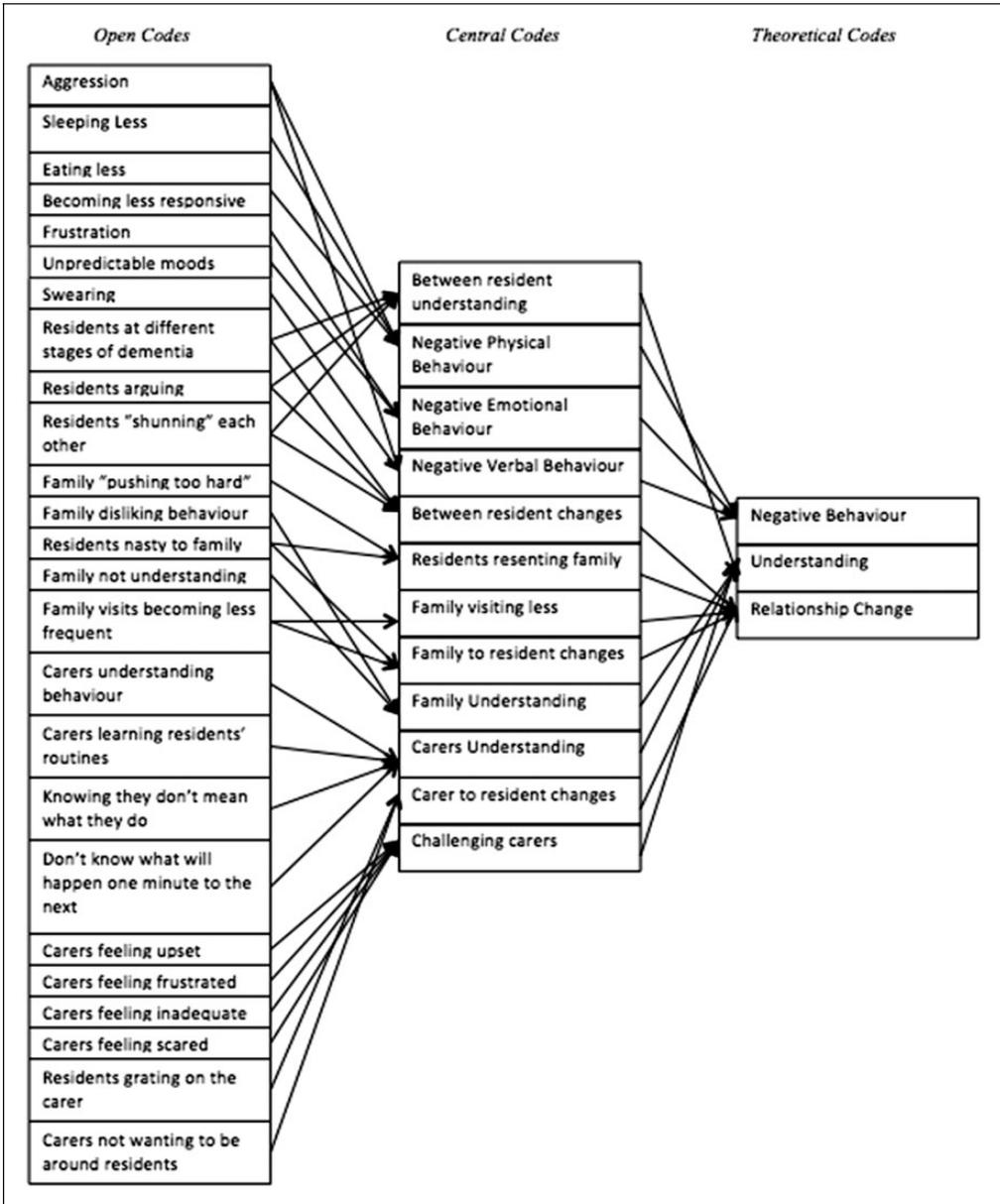


Figure 1. Representation of the open codes, central codes, and theoretical codes derived from self-report interview data using grounded theory methodology.

Others talked about the difficult behaviour that the family witnessed – several of the interviews mention ‘swearing’, ‘being verbally or physically aggressive’ and ‘playing with their food’. As a result, participants found family visits became less regular and some stopped all together – thus leading to a deterioration in the relationships. A small number of families

were reported to have worked hard to appreciate the effects of dementia and that this helped them to maintain a good relationship with the resident.

Interestingly, relationships among residents might also be noticeably affected by change. In fact, caregivers often mention how much some residents struggle to understand the behaviour of other residents. Patients might become agitated, confrontational and even aggressive and their relationships can deteriorate overtime as dementia progresses differently from person to person.

## Discussion

In this study, participants were asked about their experiences as professional health caregivers for individuals suffering with some form of dementia. It aimed to investigate this through three main aspects: experience, behaviour and relationships.

Previous research focused primarily on aggression exhibited by the patient and the impact this had on family caregivers. The current research findings have revealed the existence of a range of behavioural changes across the development of dementia. Importantly, the present study has identified the understanding of behavioural change as a crucial factor for the sustainability of the relationship between caregiver and resident. The interviews have emphasized the emotional and physical strain associated with being a professional health caregiver (Hall et al., 2014) of patients living with dementia. However, the relationship of the patient with the professional caregiver was identified as one of the most determinant factors to influence this.

These interviews aimed to understand the perceptions of professional caregivers regarding the impact of challenging behaviour on relationships of dementia patients with others and how this might influence the care they are then provided with. Furthermore, this study provided further support for previous research that has investigated the relationship changes that occur for spouses and family members (Hemingway et al., 2014; Ritchie & Lovestone, 2002) of individuals who move into a residential facility. The core category developed in this research was that 'Developing behaviour in dementia impacts relationships on a personal and professional level'.

Throughout the interviews, there was a range of behaviours identified by the participants as difficult or negative. These included disruption concerning eating patterns, sleeping patterns, mood, engagement and aggression (Hayward et al., 2012; Hooren & Waterink, 2015; Mioshi et al., 2013) which often appeared to impact the way the caregivers felt (Hall et al., 2014). A lack of understanding around these behaviours appeared to lead to negative feelings regarding those residents suggesting the finding of Stokes et al. (2014) regarding family caregivers' understanding may also be applicable to professional caregivers.

In multiple interviews, it was evident that professional caregivers felt that with the progression of dementia the behaviour presented by patients became increasingly harder to manage, with the care professionals mentioning that the behaviours manifested by patients would 'upset them' or 'makes them feel sad'. Previous literature has identified a similar pattern in family caregivers who often report similar feelings and frustration (Zwijssen et al., 2014). Such extreme negative changes were mostly identified as temporary but some professionals reported more permanent feelings. It would be important for future research to further clarify this aspect so as to determine the specific factors that influence the permanence of such negative factors and the potential impact this might have on the professional quality of life of such caregivers.

Interestingly, professional caregivers who clearly stated that they were aware that the residents were unable to control behavioural change did not report negative feelings associated with the display of such challenging behaviour (Stokes et al., 2014). This emphasizes the importance of suitable and effective training for individuals working in this area as well as of appropriate support and coping mechanisms for the challenging behaviours they are exposed to on a regular basis. It appears that the cases in which the relationships between caregivers and residents improved were those in which the caregivers felt they had gained a better understanding. The situations in which professional caregivers believed they had built a positive relationship with a resident or 'connected' described 'building trust', 'understanding' and 'respect' as the main contributing factors for this (cf. Fauth et al., 2012).

### *The importance of the relationship of the resident with their family*

In the perspective of the professional caregivers, the relatives of the patients have great difficulty understanding the behaviours presented by their loved ones. Professionals often identify a lack of engagement displayed by the resident when visited and a consequent feeling of lack of intimacy and appreciation which often results in further decline in the relationship between the patient and their family (Fauth et al., 2012; Hennings et al., 2013). Professionals report that, even when relatives have a good formal understanding of the condition, they might struggle to understand the behaviour presented by a close family member. This often has, as a consequence, a tendency to visit the resident increasingly less. As visits become less frequent, the resident is perceived by the professional as less respondent to family members and increasingly more attached to the professional caregiver instead (Hemingway et al., 2014). In fact, this clear decline of relationships between family members and residents might yet again be attributable to a lack of understanding of the condition (Stokes et al., 2014) and of the most adequate coping mechanisms that might help to mitigate such negative feelings.

### *The importance of the relationship of the resident with other residents*

Unexpectedly, as the interviews progressed, the topic of relationship change between residents arose. Several caregivers noticed that, with the progression of dementia at different rates for different patients, the understanding of behavioural change influenced the relationships among residents. Given the very limited research concerning actual relationships between dementia sufferers who live together within a facility, it is considerably difficult to predict the motives behind this. However, future research could shed further light on this topic by exploring whether such relationship changes between residents is somehow associated with their understanding of dementia as well as with their level of self-awareness in regard to their condition and resulting behaviours (Clare et al., 2008).

It is not the first time that the relevance of investigating co-resident relationships has been identified. In fact, positive relationships among residents has been identified as one of the most important predictors of life satisfaction for residents living in a care home setting (cf. Street & Burge, 2012). Importantly, this research suggests that residents living in a care setting are often confronted with other residents presenting a range of diversified care needs. This is often perceived as an alienating and even frightening factor for residents that can severely affect the quality of co-resident relationships and as a result, detrimentally affect their perceived well-being (Street & Burge, 2012). Notwithstanding, this detrimental effect might be also be

mitigated through peer support. Interestingly, residents who report high levels of support from other residents seem to be less likely to exhibit depressive symptoms in similar contexts (Yeung, Kwok, & Chung, 2013) given that peer support has been identified as a fundamental factor for psychological wellbeing in dementia (Keyes et al., 2014; Yeung et al., 2013).

## Conclusion

The present study was designed to explore the impact that behavioural changes presented by people living with dementia in care home setting produce on professional caregiver and resident relationships.

Professional caregivers have identified as part of their everyday practice an effective deterioration in the relationships between themselves as professional caregivers and the residents. Importantly, this relationship change was also identifiable, from the professional caregiver perspective, between the residents and their family members and among residents themselves.

Notably, an understanding of behavioural change in such contexts was transversally identified as a crucial factor to achieve and sustain good relationships between professionals and residents suffering with dementia.

In short, our findings seem to point to the fact that professional caregivers of patients living with dementia would benefit from more intense and in-depth training, focusing on the understanding of behavioural change across the development of the condition. This training would ideally place emphasis on the degenerative nature of the disease that has a diversified pattern of progression which might be different for each individual. Professional caregivers would hence benefit from an understanding of behavioural changes in dementia across different rates of development.

## Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The author(s) received no financial support for the research, authorship and/or publication of this article.

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