

Leadership: The key to person-centred care

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ABSTRACT

Person-centred care for elders with advanced dementia living in long-term care is essential when addressing these residents' quality of life. Occupational therapists could play a facilitative role in enhancing person-centred care, but need to ensure that caregivers, as essential care partners, are collaborators in this process. Therefore, the perspectives of caregivers would be key to a process where greater understanding and joint effort pave the way for advances in care practice. A mixed methods triangulation design was used to investigate the perspectives of caregivers with regard to occupation, quality of life and activity participation. The findings of this study indicated that caregiver perspectives and behaviour are unlikely to change if the organisation as a whole does not embrace a person-centred approach towards the caregivers. The discussion highlights specific changes needed to attain a level of servant leadership that could assist the organisation to facilitate person-centred care, focussing mostly on caregiver burnout but also including feelings of boredom of residents with dementia. This article considers the potential role of servant leadership as a driving force behind person-centred care.

Key words: Quality of life, dementia, burnout, boredom, servant leadership, restorative practices

INTRODUCTION

The dignity of elderly people with dementia living in residential care facilities is honoured through person-centred care (PCC). However, the traditional model of care, focussing on care as a regimented list of tasks to complete, still dominates the care culture in South African residential care homes¹. Consequently residents are institutionalised, a factor that leads to boredom and causes emotional impairments above and beyond the impact of health problems associated with old age². Institutionalisation creates a pathological system that also impacts on staff, especially in an environment where nurturing is neglected³. Without nurturing residents cannot be recognised as individual human beings with preferences, emotions and potential, but are often treated as *objects* who only have physical needs². Institutionalisation creates a pathological system that also impacts on staff, especially caregivers, who often suffer from isolation, helplessness and burnout³.

In recent years, occupational therapists working in residential care settings in South Africa have been challenged to assist with combatting resident boredom and caregiver burnout. The endeavour has involved supporting staff to move beyond a task-focussed orientation to a person-centred focus where residents direct their own care needs. Because of their constant involvement, the caregivers who provide 24-hour care to residents were key in initiating a process for addressing PCC. However, formal and informal in-house training, in addition to occupational therapy staff modelling PCC practice, did not ensure care that was resident directed.

Occupational therapists could play a facilitative role in enhancing person-centred care, but need to ensure that caregivers, as essential care partners, are collaborators in this process⁴. Changing the leadership approach of any organisation is a challenge in need of careful consideration^{2,5}. Therefore, the perspectives of caregivers would be key to a process where greater understanding and joint effort pave the way for advances in care practice. As facilitators of PCC, the occupational therapists, being mostly involved on a part-time basis within the residential care facility, needed more insight into the role of leadership for combatting a pathological care setting. In this article the potential role of servant leadership as driving force behind person-centred care is considered while exploring the relationship between resident boredom and caregiver burnout. The

literature review is followed by an explanation of the mixed methods triangulation study design. The results and discussion are presented simultaneously and emphasise the impact of leadership on boredom and burnout, as well as the changes needed to embrace PCC.

LITERATURE REVIEW

The role of PCC can be better understood when considering the context of the residential care and the impact of institutionalisation on caregiver burnout and resident boredom.

Institutionalisation in a residential care facility

Most residential care facilities have more in common with a hospital than with a home. Anyone who enters a residential care facility, whether to work or to visit, should do so from the perspective that they are entering someone's home, not a workplace or a medical facility⁴. This hospital perspective is due to society's view that *ageing equals decline* and therefore elderly persons are *all* in need of constant medical care². In this traditional model, the residents in residential care facilities are referred to as *patients* and the central focus is on their medical conditions. The doctor, professional nurses and therapists are the main role players within the care plan of the residents. A top-down management approach is followed and the workload is divided between the different departments^{6,7}.

Furthermore, the traditional approach creates an environment where the residents wait for the caregivers to provide routine care that is cost-effective. In this task-oriented environment, the personhood of the residents is neglected and not much attention is given to their individual needs^{6,7}. The problem with this approach is that it cannot address the three most prominent problems faced by elderly people residing in care facilities, namely loneliness, helplessness and boredom. These three problems are referred to as *the three plagues of the human spirit*^{2,5,6}. Due to the progressive nature of major cognitive disorders and continuous decline in abilities, the *three plagues* are more severe for people with advanced dementia. A loss in occupational performance components impact activity performance and can cause people with specific debilitating conditions to become deprived in terms of occupation and prone to situations where they experience sensory deprivation^{8,9}. Therefore, elderly persons with dementia are at risk of suffering from occupational deprivation and occupational injustice¹⁰. They are prohibited from



participating in meaningful activities, which ultimately lead to a decrease in their quality of life¹⁰.

The effect of institutionalisation has an impact beyond the residents and also affects the caregivers. Horton³ compares the experiences of caregivers to those of the residents. In a pathological care setting where elderly residents are lonely, caregivers feel isolated; when elderly residents feel bored, caregivers experience burnout; and ultimately all parties experience helplessness. Therefore, the three plagues for caregivers working in a residential care facility are isolation, helplessness and burnout.³ *Table 1* offers a breakdown of the three plagues for both residents and caregivers, with the suggested antidote for each plague⁶. The impact of boredom and burnout in particular are highlighted in this article.

The negative impact of institutionalisation on both staff and caregivers could be counteracted when PCC directs care practice.

Person-centred care in residential care

In contrast to the traditional model of care, a person-centred approach aims to combat the three plagues and enhance residents' quality of life^{6,11,12}. In this approach, the *patients* are referred to as residents and they are the main role players in a homelike environment where caregivers facilitate the independence and growth of the residents. In this nurturing environment, the personhood of the residents is preserved; they are free to make choices; their preferences and individuality are the main focus; and medical treatment has a predominantly supportive function, only when needed. In a nurturing care culture, caregivers know the life stories of the residents and provide residents with the opportunity to give as well as to receive care. The strict routine of the traditional care model is replaced by variety and spontaneity.

Person-centred care facilitates the building of strong relationships between leaders and caregivers within an organisation. An important part of this approach is to break down the leadership hierarchy and create a decentralised view of leadership. This enables a nurturing environment where decisions are made in conjunction with the staff and residents; where the needs of the residents are priority⁶. Staff members in a nurturing setting report to each other and to residents, not to the leadership of the residential care facility. Person-centred care also allows for the development and empowerment of the caregivers and the opportunity to take initiative and to be creative^{6,13}.

The caregivers are the persons with the most potential to have a constant impact on the lives of the residents, therefore they have the greatest capacity to impact on the residents' quality of life. When a residential care facility aims to advance PCC, authoritarian leadership styles should be replaced with leadership styles that

support PCC principles¹⁴. This development is key to promote a nurturing care culture at an organisational level⁶.

Leadership

There is inadequate literature on the impact of leadership styles on person-centred care. However, the importance of motivation/volition and values as part of life roles for growth and development is a well-documented occupational therapy perspective¹⁵. Hall and Tonna¹⁴ developed a map recognising the values of an organisation, its leadership and staff members. The map is based on theories of growth, volition and values that endeavours to link the association between leadership and nurturing environments¹⁶. See *Table II*.

The value map suggests four progressive phases of human development namely surviving, belonging, self-initiating and interdependence¹⁴. Surviving is seen as the most basic of the phases and interdependence as the most developed. Each phase is divided into two stages, with goals and means which represent the values of the particular phase. The phases are associated with seven leadership styles, also in progressive order: authoritarian, benevolent, manager, facilitator, collaborator, servant and visionary. The Hall-Tonna Values Map¹⁴ indicates that, in the context of residential care, the authoritarian leadership style correlates with goals and means that focus on the self, physical care and comfort. When the characteristics of PCC are compared with the values map, it is evident that the self-initiating phase aspires towards PCC. The values of this phase focus on community interaction, interpersonal relationships, working together, development, recognising individuality, and sharing responsibility. The leadership style associated mostly with the self-initiating phase is servant leadership. Therefore, servant leadership supports the principles of PCC. In order to achieve PCC, organisations should promote a servant leadership approach rather than enforcing a climate of dictatorial authority.

According to the Hall-Tonna values map, authoritarian leadership is the most basic form of leadership with a potentially rigid impact on the care culture of an organisation¹⁴. An authoritarian leadership approach implies that leaders take total control, their goals are aimed at their own instead of the organisation's benefit and that they are more focused on the task at hand than the people doing the work¹⁷. In essence, the authoritarian's motivation is aimed at the lower levels of Maslow's hierarchy of needs, namely, addressing personal physical needs of food, warmth, shelter and safety^{14,18}.

At the other end of the leadership continuum is servant leadership¹⁴. The concept suggests that servant leaders are dedicated to the development of their followers to ensure that each follower reaches his/her full potential^{19,20}. The impact of servant leadership

Table I: The three plagues of residents and caregivers

Resident Plague	Antidote	Caregiver Plague	Antidote
Loneliness	Meaningful relationships and companionship	Isolation	Emphatic leadership relationships
Helplessness	Giving and receiving of care, making choices	Helplessness	Sharing of knowledge and decision making
Boredom	Variety, spontaneity	Burnout	Empowerment, education, emotional support and creativity

Table II: Hall-Tonna Values Map (adapted)

Phases	Phase 1: Surviving		Phase 2: Belonging		Phase 3: Self-Initiating		Phase 4: Interdependent		
	Safety	Security	Family	Institution	Vocation	New order	Wisdom	World order	
Leadership	AUTHORITARIAN		BENEVOLENT		MANAGER	COLLABORATOR	FACILITATOR	SERVANT	VISIONARY



on caregivers in a residential care facility implies that the leaders will be the mentors rather than managers - the servant leader persuades others rather than forcing them to do a certain task²¹. A mentoring relationship between the leader and the caregiver could ultimately serve as an antidote to isolation. If caregivers are included in decisions, they can take ownership of their work, because their opinions are valued²¹. Ownership would combat the plague of helplessness.

The servant leader could also explore the unique potential of each caregiver and assist in developing areas of strength and compensating for areas where the caregivers experience challenges²¹. The implementation of this principle could lead to the empowerment of caregivers¹⁹, serving as an antidote to feelings of burnout³.

The main focus of servant leadership is service to their followers; in return they expect their followers to extend this by serving others^{20,22,23}. This implies that if the leadership of a residential care facility serves its caregivers, the caregivers will serve the residents. If the leadership practices PCC when dealing with the caregivers, the caregivers will serve the residents through PCC¹³.

Therefore, within the context of the Hall-Tonna Values Map¹⁴, servant leadership creates the potential for caregivers to build meaningful relationships with residents, limiting the plague of loneliness. Other potential benefits of servant leadership would be including residents in decision making, promoting resident-directed care and combating helplessness of the residents. The nurturing environment within such a care culture would discard strict routines, allowing variety and spontaneity based on real-life situations, thus eliminating feelings of boredom experienced by the residents.

METHOD

Problem statement

PCC programmes were individually designed to enhance the quality of life of residents with dementia and meant for the use by all care partners, especially caregivers, as they spent the most time with the residents.

Although most of the caregivers were perceived as dedicated to their work, PCC training attempts appeared unsuccessful to enhance quality of care.

Research question

This study explored the caregivers' pre-conceived ideas regarding person-centred care, occupational engagement and quality of life for people with dementia.

Objective

The objective of this collaborative research investigation was to describe the caregivers' pre-conceived ideas of occupational en-

gagement, person-centred care and quality of life for people with dementia.

Research design

A mixed methods triangulation study design²⁴ was used. The pre-dominant focus of the study was qualitative in nature as eight staff members were interviewed at length to gain an understanding of their personal perspectives. The qualitative responses were then compared and contrasted with quantitative responses to determine the relationship between the two.

Sample

Eight (n=8) female caregivers who participated in the study were a comprehensive sample of all permanent caregivers working in the special care unit of a residential care home in the Free State. Purposive sampling ensures that all available resources are used regardless of the level of saturation and was therefore applicable to this study in order to give each of the caregivers a chance to voice their perspectives²⁵.

The caregivers' ages ranged between 30 and 46. None had any formal training in the work expected of them. Six caregivers were Sesotho-speaking, one caregiver was Setswana-speaking and one caregiver was isiXhosa-speaking.

At the time of the study, these caregivers cared for a population that consisted of mainly Afrikaans and English-speaking residents between the ages of 40 and 96, with two Sesotho-speaking residents. There were 21 residents at the time of the study.

Data collection

Qualitative and quantitative data were collected simultaneously. The open ended questions used to collect qualitative data were posed directly after each participant's response to each closed-ended question. Two data sets were produced that were analysed separately and compared afterwards, a process true to the mixed methods triangulation design²⁴.

The structured interview questionnaire used for quantitative data collection contained sections focussing on demographics, perceptions of care quality and causes of aspects that enhanced or detracted from PCC. The structure of the questionnaire is summarised in *Table III*.

Data analysis

Qualitative

The interviews were recorded as audio-visual material, transcribed and member-checked. Observation was used to verify verbal and non-verbal messages of the caregivers^{24,26-27}. Data were analysed and two co-coders were involved to enhance trustworthiness²⁸.

Table III: Questionnaire Structure

SECTION	DESCRIPTION
Section A	Demographic information
Section B	The questions in section B were focussed on the perception of the participants relating specifically to the SCU, the residents and the families of the residents. The options of these questions were ranked by the participants. After placing the options in the correct order, they also had to indicate whether the option occurred always (1), sometimes (2) or never (3). These values were multiplied by the initial ranking position that the participant indicated. Therefore, the lower the ranking value, the higher the rank for all of the questions in Section B.
Section C	Section C also consisted of questions with different options and the participants were allowed to choose one of the answers.
Section D	With these questions the researcher determined the perception of the participants regarding the names of the residents and how to address them.
Section E	Section E contained questions to determine whether the participant believed that a person-centred approach was followed in the SCU. If the participant believed that a person-centred approach was followed, she was asked to give an example.
Section F	The questions grouped into Section F were aimed at determining whether the participants viewed the person-centred care, occupational engagement and QoL of the residents according to the person-centred approach or the traditional model without the person-centred approach. Each question had two or three options of which one or two represented the person-centred approach.



After the data sets were read thoroughly and the coders were familiar with the content, the following process, described by Creswell²⁹, was followed:

- ❖ Verbatim quotes were underlined and coded in the transcriptions.
- ❖ The codes were indicated on a separate diagram.
- ❖ The codes were clustered into categories.
- ❖ The categories were then clustered into themes.
- ❖ The coders also marked the responses of caregivers who spoke from first-hand experience to determine which pieces of data bore the most weight.

Quantitative

The quantitative data were analysed by the Department of Biostatistics, University of the Free State and produced frequency tables³⁰.

Reliability and validity

Qualitative

Adequate time was spent in the interview to obtain rich data from the caregivers. A literature study was done on the situation of the caregivers, occupational engagement and quality of life to ensure that relevant questions were asked. Although all of the caregivers were fluent in Afrikaans, a translator was available to eliminate any language barriers that occurred. These measures ensured prolonged engagement during the interview.

Investigator triangulation was utilised as the two co-coders and the researcher independently analysed and interpreted the data from the interviews and observations. The process was repeated until the researcher and co-coders agreed on the results. The two co-coders were both occupational therapists who were chosen on account of their qualitative research experience, as well as their experience working with caregivers. Methodological triangulation^{24,31} was utilised and both qualitative and quantitative methods of study were followed. Observing and interviewing all the caregivers promoted data source triangulation.

Data were retrieved from audio-visual material and field notes. Both techniques ensured that contradictions between caregivers' verbal and non-verbal messages could be determined. An inquiry audit by a fourth expert addressed confirmability of the study. She reviewed the codes and themes established to confirm that the categorisation of the data reflected the transcript contents.²⁸

Quantitative

To increase the reliability of the structured interviews, variables were clearly defined within the questionnaire design. Specific questions were used to measure each variable and a pilot study was done prior to the execution of the study to test the reliability of the interviews³². It was possible to determine the reliability of most of the questions on the interview schedule statistically, because of the nature of the items and the small study sample.

A thorough literature study ensured that all the aspects underlining PCC, occupational engagement and quality of life were included in the questionnaire. A pilot study contributed to the content validity. Triangulation of the data was used between Section B (relating to the perceptions of the caregivers regarding the special care unit, the residents and the family of the residents) and Section F of the structured interview questionnaire as similar themes emerged from the two sections³³.

All the questions included were directly linked to PCC, occupational engagement and quality of life and/or aimed to establish a link between the two concepts. This factor enhanced face validity.

Upon completion of the interviews, the researcher engaged member checking. Each caregiver was provided with a copy of her completed questionnaire to confirm that the data was a just recording of her perceptions.

Ethical considerations

Approval to conduct this research was obtained from the Ethics Committee of the University of the Free State and the researcher obtained written consent from the managers and caregivers at both facilities for execution of the pilot and research phases of the study.

Pseudonyms were used to protect the participants' and other staff members' identities. The facilities and caregivers received feedback on the results of the study.

FINDINGS AND DISCUSSION

A comparison was made between the third plague for residents (boredom) and the third plague for caregivers (burnout) as indicated in *Table 1*. These problems are paralleled as antidotes for them are similar.

Boredom and burnout are the consequences of a life without creativity and growth. Both caregivers and residents are in need of challenges that living offers in every stage of life¹⁸. The findings and discussion focus on burnout and boredom to illustrate the importance of a change in leadership approach. Afrikaans quotes were translated to English. The number of the caregiver (e.g. C1) is indicated after each quote. Translations are also indicated (e.g. C1t).

Burnout

Burnout, as one of the three main problems for caregivers, is combatted when empowerment, education, emotional support and creativity are facilitated².

Empowerment

The perceptions of the caregivers were that the organisation was in control and that they were not afforded the opportunity to take initiative. Feelings of disempowerment were recorded, "*I would like the professional nurse to understand that I also know something about dementia and that my ideas will also be good for the patient.*" (C3t)

The caregivers mentioned that surveillance cameras were used in the special care unit. They were scared of being captured on camera while attempting new methods for which they could be criticised, "*Yes, if there is a problem Sr. X goes to the camera and checks on you.*" (C1t)

The fact that the caregivers were afraid to try new methods when working with the residents was the predominant reason indicated from a list of eight that restricted them from facilitating independence of the residents. Furthermore, the organisation appeared to discourage new ideas by reminding caregivers of the possible negative consequences, "*...every time you come up with a new idea, they will ask you: 'What if the patient gets hurt? Then you will have to take the blame.'*" (C2t)

The organisational culture guides the behaviour of the caregivers and therefore the caregivers operate within the boundaries of that culture and are unlikely to take initiative⁶. Power² states that the organisational structure in a residential care home often undermines and belittles the insight of the caregivers. This is the result of an authoritarian leadership approach that aims to take all control away from the caregivers¹⁴. Chenoweth *et al.*³⁴ emphasise the importance of facilitating the learning of the caregivers in an environment where they are respected and not criticised. In contrast, the servant leadership approach¹⁴ encourages caregivers to undertake stewardship, to be creative and to grow. The small efforts of caregivers to take initiative cannot be sustainable against the force of the organisation, unless the leadership mentors and encourages caregivers.

Education

Five of the caregivers working in the special care unit matriculated, two completed Grade 11 and one caregiver completed Grade 7. None had formal tertiary training.

Although caregivers did receive in-service training, one of the caregivers very strongly questioned the feasibility of the training. However, she indicated that some training was valuable to provide new knowledge. She valued the knowledge, but did not apply this knowledge practically, "*... at the Alzheimer's training we learned how to work with people with Alzheimer's.*" (C7t)

"*We try to do it in the unit. We cannot do everything, because sometimes the book says one thing and you cannot follow the book for everything, because those people are really difficult.*" (C7t)

The above findings are supported by the uncertainties of the caregivers as to how to analyse an activity to make it possible for



the residents to participate in – this was ranked as the sixth most important reason for not facilitating independence.

It appears that caregivers were at an educational disadvantage in performing the complex job of caregiving. None were formally trained and although some of them believed that they did apply the principles of the in-service PCC training, they chose to do everything for residents within the set routine: “So we do, we do it for them so that we can knock off.” (C3t)

Research confirms that deficient knowledge and perceived inadequate training could be a source of stress for caregivers and that dementia-specific training is one of the best ways to reduce stress for caregivers working with people with dementia³⁴⁻³⁵. Stress reactions of the residents cause low morale and a burden of care for caregivers, but can be counteracted by the provision of in-depth knowledge of dementia care³⁵⁻³⁹.

When the caregivers do not view what is expected of them as feasible, it causes feelings of powerlessness which adds to work stress⁴⁰ and limited job satisfaction.⁴¹ Furthermore, Zimmerman *et al.*⁴² report that trained caregivers are more prone to provide PCC. Watts⁴³ confirms that the application of knowledge is a process that happens over a period of time and through a combination of formal training (including effective guidance from a mentor) and learning through trial and error. According to Du Toit and Surr,¹ staff should experience being treated in a person-centred way so they can experience the benefit thereof and apply it.

Therefore, it can be concluded that providing PCC to a residential care facility means a move towards a servant leadership approach that focuses on enhancing the knowledge and educational level of the caregivers.¹⁴

Emotional support

The caregivers were of the opinion that they suffered under a very high workload caused by the understaffed facility and had insufficient time to perform their daily duties: “Sometimes we cannot even finish everything” (C7t). The high work load was given quantitative preference as evidence of why the caregivers did not facilitate independence of the residents.

The quantitative data indicated that the fact that caregivers had frequently been exposed to the death of patients meant that they did not want to become attached to the residents, and was the reason why they did not take initiative. The emotional burden caused by the death of the residents took their toll on the caregivers: “...I loved that Oupa very much...the day when that Oupa...oh I was so heartbroken...I just prayed that it should pass.” (C1t).

In spite of the heavy burden caused by the workload and the death of the residents, some caregivers believed that they were not allowed to experience work stress, “Now if you are working there, you are not allowed to have stress.” (C5t). Therefore, it seemed that they suppressed their negative emotions in an attempt to control their stress levels at work, “Mmm, you may not say anything, you do not answer, you just keep quiet.” (C1t).

Instead of being a source of emotional support for the caregivers, the organisation encouraged them to take ‘mental health leave’: “No, the professional nurse tells you, when you are very tired, to just phone and not come to work.” (C5t).

Once again the qualitative data shows an authoritarian approach to leadership aimed at meeting physical needs as opposed to emotional needs¹. Caregivers were deprived of the opportunity to share their emotions and experienced little emotional support from the organisation. If caregivers were to experience emotional support that eliminates burnout, it could enhance their relationship with the organisation and they would be more likely to provide emotional support to the residents. Emotional support is a priority of a servant leader and could eliminate the feeling of burnout¹⁴.

Creativity

The caregivers reported that the repetitive nature of care tasks led to boredom. In addition, the organisation did not afford the caregivers the opportunity to take initiative and to be creative. Quantitative evidence indicated that the lack of opportunity to be creative was an important reason why caregivers did not take

initiative. The monotonous routine was a factor that caused stress and intensified burnout, “Yes, you do the work, one thing every day. You become tired of it.” (C4t).

Literature supports the opinion that care can be monotonous, but also indicates how PCC could impact such situations positively. Repetitiveness of a job certainly has a negative influence on work stress⁴⁰, but job satisfaction can be greatly enhanced by the application of PCC². Therefore it is concluded that the controlling routine associated with authoritarian leadership¹⁴ should be replaced with a supportive environment that encourages creativity to prevent burnout of caregivers.

Boredom

Residents were influenced by caregiver burnout. This section of the results focusses on variety and spontaneity as the antidotes to the feeling of boredom for residents.⁶

Variety

Caregivers understood some of the positive benefits of activity participation. This was confirmed by the quantitative evidence that indicated that all of the caregivers recognised that meaningful participation in activities enhanced positive emotions. However, not only was activity participation not enforced by the organisation (activity participation was ranked least important on the priority list of the organisation), but the caregivers also felt that the organisation sometimes discouraged activity participation, “...because she wants it to be quiet”. (C4t).

Literature confirms that the physical and psychological benefits of activity participation for residents with dementia are numerous,⁴⁴ but that organisations often do not view this as a priority⁴⁵. Stress reactions are reduced when each resident’s individuality and life story are taken into account to meet their occupational needs⁴⁶. Activities provide opportunity for success and enjoyment and decrease the development of unnecessary disability, thereby adding to general well-being⁴⁷.

Organisations often neglect the right of the residents to participate in meaningful activities when they are physically cared for.¹ Power² also confirms the low priority of activity participation for the caregivers and therefore states that they are prone to isolate the tasks that their job entails and perceive anything other than these tasks as an added burden. In addition to this, Anderson, Taha and Hosier⁴⁸ report that the focus on tasks associated with physiological needs may be explained by the high demands on the caregivers in terms of the workload that results in the neglect of PCC, and in turn results in enhanced dependence of residents.

Spontaneity

It appeared that a strict routine was followed in the special care unit that allowed little spontaneity: “When you go to work, you get a certain, uhm, sequence to follow.” (C3t). Caregivers further were of the opinion that the residents experienced fewer memory problems within a fixed routine:

“The other reason is that we do not want the residents to be exposed to different things too much, causing them to not remember.” (C4t).

The actual events in the special care unit showed that the residents were bathed at 04:00 in the morning: this was not part of their routines before entering the residential care home. The caregivers reported that the strict routine that was followed was unrealistic, especially in terms of the time that the residents were expected to wake up in the morning: “Because they are woken so early, like four o’ clock to wash, but then they must wait until eight o’ clock to eat.” (C8t).

Literature appears to favour a relaxed regime to support a more home-like environment for residents. Kada *et al.*⁴⁹ found that 93.1% of caregivers were of the opinion that a firm routine is very important in dementia care as it may enhance memory. Many other authors, like Harmer and Orrel⁵⁰ and Power², argue that a routine caters more for the needs of the caregivers and organisation rather than those of the residents; consequently, these routines and regimes often violate residents’ needs. Hung and Chaudhury⁵¹



report that an unrealistic, inflexible routine takes away residents' control over their own actions and leaves them powerless and aggressive. Verbeek *et al.*⁵² actually recommend that staff working in small care facilities should experience more independence and freedom in deciding the day's schedule. They should be allowed to plan the day according to the individual preferences of the residents; this in turn leads to the work being less challenging and strenuous as caregivers can then personalise the care. A less strict routine will make way for spontaneity that is essential to turn around the residents' feelings of boredom.

The quantitative data showed that the caregivers knew residents wanted to move around. However, the caregivers were of the opinion that one of their main priorities was to keep the residents safe and comfortable at all costs, a perception that diverted caregivers from allowing spontaneity: "No, I think as I have said I should take care of them so it is my duty to see if everything is okay with that patient, that she doesn't get hurt or she is safe and clean, neat." (C6).

Ayalon *et al.*⁵³ have found that caregivers believe more than any other profession that supervision and seclusion are important in providing effective care to people with dementia. Harmer and Orrel⁵⁰ stress that safety is a very high priority for caregivers. Data from Dementia Care Mapping research in South Africa presented evidence that the caregivers used tray tables as restrictions for up to six or more hours per day, which prevented independence and residents' need to move¹. Being restricted makes residents feel powerless and disrespected as human beings⁵¹. Therefore, the focus of care should be on the person as a *human being where* PCC preserves the personhood of people with dementia¹ rather than practices that encourage helplessness. It is important to note that the safety of the resident should always be a priority for any organisation, but it should not restrict the residents' opportunity to interact with the environment. Environmental adaptations should be made to accommodate the residents' needs.

Limitations

Despite the fact that all full-time caregivers at the facility were included in the study, the small sample size limits the relevance of the findings for other long-term care institutional settings. Future research should expand the topic and include more facilities.

CONCLUSION

The research focused on the caregivers' perceptions of occupational engagement, PCC and quality of life and revealed the restrictive impact of leadership approaches on PCC. A paradigm shift towards servant leadership could support PCC in residential care facilities and serve as the driving force to combat burnout of caregivers and boredom of residents. Although the impact of leadership in residential care homes needs more intensive research, servant leadership could potentially drive PCC and restore human dignity of the caregivers and the residents. Managerial leadership might not inspire PCC, but investment in the work force would reveal that any employee could be a leader.

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COMMENTARY

Inside Guillain-Barré Syndrome: An occupational therapist's perspective

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ABSTRACT

Occupational Therapists working with patients with Guillain-Barré Syndrome (GBS) are tasked with collaborating with the patient to achieve maximal functional recovery. Although much has been published about recovery after GBS from a scientific perspective; this article combines occupational therapy principles with the personal experiences of an occupational therapist who herself suffered from GBS. This commentary outlines important considerations for providing intervention to patients with GBS and offers insights into the emotional and psychological aspects of coping with GBS.

Key words: Guillain-Barre Syndrome, personal experience

INTRODUCTION

As occupational therapists we are faced with the unique challenge of enabling patients to adapt to altering life circumstances after contracting disabling health issues and to improve their level of adaptive functioning. We are trained not to be sympathetic by telling patients that we *know how they feel* because without any firsthand experience, there is no way that we could understand their situation¹. I contracted Guillain-Barré Syndrome (GBS) after returning from an overseas holiday and within 6 days from my first symptom I was completely paralyzed; requiring maximal nursing care in the ICU. I believe that my personal experience with this condition has given me insight into being a patient; extended my understanding of GBS; and improved the quality of my intervention as a therapist.

GBS is an auto-immune condition with an average incidence rate of between 0.35 and 1.8/100 000 people per year^{2,4}. GBS is an acute demyelinating peripheral polyneuropathy characterised by a symmetrical progressive muscle weakness and sensory loss². Research on the causes of GBS include preceding gastrointestinal or respiratory infections in 40% to 70% of cases. Trauma, surgical procedures and childbirth preceding only a small percentage of incidents³⁻⁶. Viral infections and inoculations have also been cited as potential causes⁶.

The condition typically has a rapid, symmetrical progression that reaches a plateau eight days to four weeks after initial onset^{4,7,8}. The rate and extent of recovery is variable but better outcomes have been associated with younger age at onset, slow disease progres-

