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Dementia In Long-Term Care Homes: Direct Care Workers' Difficulties

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Abstract

Increasing numbers of people with dementia are being admitted to long-term care facilities. Behavioural and psychological symptoms of dementia (BPSD) are particularly challenging to care homes which are commonly characterised by a low-skilled workforce. The increasing demand for higher quality dementia care emphasizes the need to address the Direct Care Workers' (DCWs) difficulties, as this can inform the development of effective training interventions. This study aimed to explore the difficulties faced by DCWs caring for people with dementia in long term care homes. A qualitative cross-sectional study was conducted with 58 DCWs (female; mean age 44.63 ± 2.32). Eight focus-group interviews were performed to collect data. All interviews were video-recorded, transcribed and submitted to thematic analysis by two independent judges. Main difficulties faced by DCWs were related to: i) lack of time to provide personalised care and interact with residents, particularly during morning care; ii) management of the BPSD (e.g., agitation); iii) lack of knowledge about dementia and its symptoms, evolution and available treatments; iv) communication with residents; and v) stress and burnout related to BPSD. The findings underline the importance of training programmes for DCWs that provide both information and skills for dementia care that can be implemented during personal care tasks, and support to deal with stress and burnout. This is essential as training interventions are usually targeted on DCWs' care knowledge and skills, neglecting the psychological pressure experienced by these workers.

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1. Introduction

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Dementia is a leading cause for admission of older people to long-term care (LTC) facilities [1] affecting at least 80% of the residents [2]. The majority of the individuals are institutionalised during the later stages of dementia, when behavioural and psychological symptoms of dementia (BPSD) (e.g., agitation or apathy) are more significant [1]. Consequently, BPSD are highly prevalent in care homes, imposing major demands on Direct Care Workers (DCWs) who provide the most hands-on care to these residents. Yet, DCWs are often under-prepared for effectively managing the care required, revealing low educational attainment and inadequate training on dementia [3].

The growing demand for high-quality care to an increasingly number of people with dementia, underscores the need for training interventions to deal with the shortage of competent DCWs [3]. In order to enrich the development of effective training interventions, previous knowledge about potential participants' experiences should be acquired. Thus, the present *study sought to understand* the difficulties faced by DCWs' caring for people with dementia in LTC facilities.

2. Methods

2.1. Design

A qualitative cross-sectional study was conducted with DCWs of 4 LTC facilities of the central region of Portugal, between November 2011 and December 2012. Ethical approval was previously obtained by the Ethics Committee of the Health Sciences Research Unit: Nursing (UICISA: E), hosted by the Nursing School of Coimbra, Portugal.

2.2. Procedures and participants

Four LTC facilities were contacted and the service managers were informed about the study plan. All facilities agreed to participate. The service managers were asked to identify DCWs who met the following inclusion criteria to: i) provide regular personal care to people with dementia (e.g., bathing, dressing and toileting); ii) work at the facility for at least 2 months. Temporary workers, trainees, DCWs working only on the night shift, other health and social care practitioners (physicians, nurses and social workers) were excluded, as they spend short periods of time with the residents. After this procedure, potential participants were clarified about the purpose of the study and the voluntary nature of their participation. All the 58 DCWs agreed to participate. Written informed consent was obtained prior to any data collection. Demographic data about the DCWs (Table 1) shows that participants were all female, mainly married (67.2%) and with an average age of 44.72 ± 9.06 . Nearly half of the participants (46.4%) had the primary and middle school and 41.3% the high school. The average length of employment was 9.61 ± 3.72 years.

2.3. Data collection

Data were collected through eight focus groups interviews (two in each LCT facility), ranging in size from 5 to 12 participants. The interviews were conducted by a trained gerontologist in a quiet room of each facility, so that DCWs felt that they could speak freely without being interrupted. A semi-structured interview guide was developed to explore DCWs' perspectives. The following questions were considered: *How do you feel about taking care of residents with dementia? What are your main difficulties/concerns?* The role of the moderator was to encourage participants' reflection, using probes to clarify or elaborate their responses (e.g., 'can you explain further?') while keeping a friendly and non-judgemental attitude. Interviews were video-recorded and had an average duration of 43.21 ± 10.08 minutes.

2.4. Data analysis

Focus-group interviews were transcribed *verbatim* and submitted to thematic analysis by two independent judges (1st and 4th authors), as follows: (1) the text was read several times to construct a sense of the text as a whole; (2) preliminary codes were created, closely reflecting the interview questions; (3) codes were organized into categories and then integrated into major themes; (4) the categorization was compared and discussed between the two judges until reach a consensus; (5) a critical feedback was performed by the other authors. Data was processed using computerized qualitative data analysis software - webQDA (University of Aveiro, Portugal).

Table 1. Background characteristics of DCWs

Outcome	Direct Care Workers (n=58)	
	N	%
Gender		
Female	58	100.0
Age		
19-28	2	3.4
29-38	14	24.1
39-48	20	34.4
49-58	19	32.7
≥59	3	5.1
M (SD)	44.72	9.06
Marital Status		
Married	39	67.2
Widowed	3	5.2
Single	4	6.9
Divorced/separated	9	15.5
Other	3	5.2
Education		
Primary school	15	25.8
Middle school	12	20.6
High school	24	41.3
College degree	1	1.7
Other	6	10.3
Working time (years)		
≤1	4	6.8
2-6	10	17.2
7-11	32	55.1
≥12	12	20.6
M (SD)	9.61	3.72

3. Results

Seven categories have emerged and were clustered into two key-themes: inability to provide the ideal care and manage residents' behaviours. Five subthemes - under time pressure and workload; lack of emotional support; lack of knowledge about residents' profile; lack of information about dementia and difficulties in communicate – were linked to inability to provide the ideal care. Emotional and physical exhaustion were related to manage residents' behaviour. Results will be discussed regarding the key-themes and supported by reference to illustrative extracts from the data. All names have been changed to protect participants' anonymity.

3.1. Failure to provide the ideal care

A major difficulty faced by DCWs was related to the inability to perform the care they wished to perform: less instrumental and more individualized. According to several participants, this was a consequence of the time pressure and workload that emerge from the '*increased number of dependent residents*' and the '*shortage of staff*'. The DCWs wished to be able to foster the residents' autonomy, communicate and promote their active participation during care routines, and feel frustrated when they had no opportunity to achieve this. Some interviewees noted that the morning care, contemplating basic daily activities (e.g., bathing or dressing), was the most difficult moment '*to be completely committed to the resident*'.

"I regret not having more time to talk with them [residents with dementia]. We take care for their hygiene,

we feed them, lay them and I feel that they wish to talk with us, they want to tell us something and we don't have a bit of time to be with them and to hear them." [Maria]
 "We should have more time to properly care for them... without any stress or rush, with enough time to talk with them, to encourage them to do something." [Luciana]

A second threat to the quality level of care was related to DCWs' need of being '*recognised*' and '*valued*' by their emotional demanding work. Many participants missed acknowledgment from their managers and feel that their work is unappreciated. They reported that if their emotional needs were attended they were more likely to be in a state of better well-being which could lead to better care:

"It's more mental exhausting being in that floor [a floor predominantly occupied by residents with dementia]...makes you laugh and cry. If you don't feel healthy, if you don't feel well (...) even here if you are not encouraged, valued and respected by the work you perform, it becomes harder. We should have psychological support." [Ana]
 "Sometimes I show to others that I'm strong, but in other days I don't feel so well... and if I'm not well I can't care of them as it should be (...)" [Teresa]

Antecedent information about the person's background, lifestyle, preferences and current conditions was also pointed out as being required, with a few participants recognizing that if this information was available they would improve their relationship with the resident and the quality of care provision. Overall, it was through *experience* and '*working time*' that DCWs became more aware of the residents' characteristics, preferences and values:

"I think we don't know our residents. (...) We do not know what their preferences were before their admission to this care home. (...) If we some more information about them perhaps things would be done differently. We involve them all in the same kind of recreational tasks and only through time we realize what they like and dislike. If we were informed from the moment of their admission about their story it would be easier...we could start talking of what they liked". [Luisa]

Similarly, participants were acutely aware that they lack information about dementia, dementia-related behaviours and how to manage them. DCWs noted that such information would impact care provision and mitigate feelings of uncertainty about their skills:

"Why the resident becomes so aggressive? Why he cries all day long? If we are caring for him or her... well why are they reacting aggressively? If they have the same disease why they react so differently? These are the questions that we don't know how to answer". [Paula]
 "We are aware to be short of some skills that prevent us from caring as we should." [Manuela]
 "(...) we don't know if the things we are doing are hurting them". [Luciana]

Finally, the ability to provide a better care was compromised by communication problems with residents. Overall, DCWs emphasised that they are less likely to interact with dementia residents than with the non-cognitively impaired ones. This was related to the fact that residents with dementia '*barely speak*' and with DCWs' doubts to realize if their speech is being understood:

"We provide better care for people with intact cognitive capacities because we can talk to them." [Sonia]
 "Mrs. F. when we say "let's go" maybe she does not understand anything of what we are saying. That's why it is so difficult" [Palmira]

3.2. Residents' behaviour

Several DCWs felt that their physical and psychological well-being was negatively affected by the strain of caring for people with dementia. According to participants caring for people with dementia was more difficult than caring for residents with other conditions. Terms like '*exhaustion*' or '*stress*' were frequently reported.

BPSD were relatively common and poorly tolerated by participants. Wandering has been seen as a particularly

challenging behaviour to be stopped. DCWs reported great difficulty in coping with this symptom, feeling often forced to proceed against their or residents' will. Physical restrictions were seen as adverse but often realized as the only alternative to 'get the work done' and the 'residents' safety':

"It is difficult when they are wandering, when they want to go outside and we have to be after them all the time. We ended up having to restrict them, or otherwise we can't do anything." [Mariana]

Yelling, stealing accusations, agitation or repetitions were also described as challenging behaviours. DCWs stressed their daily struggle to manage these symptoms and the impact of this in their family life:

"It's exhausting hearing for 200 times the same things and trying to explain ... and then we know at what time they will start. One resident wants to see the mother ... we do not say 'your mother is not here' we put the receptionist saying 'I've already called your mother, she told you to start eating'. Being emotionally well to succeed, to manage all this, it's complicated." [Ana]

"It is easier to distract a person without dementia that remains noiseless while watching TV. He is certainly not demanding as a person who is yelling all day (...) You have a person with dementia that yells all day long, another one that cries,...it becomes psychologically exhausting. It exhausts us. You arrive home to be with your family and you are exhausted." [Gabriela]

Some respondents also felt that caring for residents with dementia has a considerable cost to their own physical health:

"It is physically exhausting. Even when they can put their feet on the floor they do not facilitate our work" [Luisa]

4. Discussion and conclusion

The results provide relevant knowledge about the difficulties faced by DCWs when caring for people with dementia. These were related to the lack of ability to perform the ideal care given the time-pressure, lack of emotional support and absence of information and preparation to deal with dementia. Additionally, feelings of emotional and physical exhaustion that emerge from residents' behaviours were emphasised. These findings are of great significance as they provide important insights to design effective training interventions.

Providing DCWs with information about dementia and competences to deal with BPSD, as well as ways to cope with frustration, stress and burnout might be an important lever to deliver better care. Psycho-educational interventions, albeit underdeveloped in the context of formal care, can be helpful for DCWs as they add to the traditional training programmes (training alone) a supportive component that addresses their emotional needs. Supporting DCWs to cope effectively with stress and burnout is of paramount importance, as it has been shown that staff strain is associated with less willingness to help residents, low optimism and negative emotional responses to residents' behaviour [4]. Organisationally, the present study suggests that the availability of adequate support managers is a key factor in improving the quality of care to residents with dementia. Managers can, for example, hold open channels of communication (e.g., by maintaining DCWs informed about residents' biography), certify that DCWs have enough time to maximize the use of residents' abilities during personal care tasks or encourage and give feedback on care practice. The findings reflect the hierarchical management structure of LTC facilities and the emphasis placed on organisational needs rather than on emotional issues. This kind of 'culture' had determined a dearth of adequate training and support for DCWs. Thus, extending the focus of interventions to all levels of staff might be necessary in order to raise awareness across the entire organization.

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