





REVIEW ARTICLE

Supportive care for older people with dementia: socio-organisational implications

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Abstract

For many years, dementia care has been dominated by the standard medical approach, in which dementia is treated mainly with drugs, such as anti-anxiety, antidepressant and anti-psychotic medications. With the aim of seeking effective treatments for patients with dementia, over the last years, several contributions have criticised the pervasive use of drugs for the management of behavioural and physiological symptoms related to dementia, proposing personalised interventions aimed at supporting patients and their relatives from diagnosis until death. With particular reference to long-term settings, in this work, we aim at understanding the organisational implications of three types of interventions (labelled supportive care interventions – SCIs) that have characterised this shift in dementia care: person-centred, palliative and multi-disciplinary care. Conducted by following the integrative review method, our review underlines how SCIs have controversial consequences on the quality of care, the care-givers' quality of life and cultural backgrounds. After an in-depth analysis of selected papers, we offer some considerations about the implications of SCIs for long-term care organisations and future research directions.

Keywords: dementia; long-term care facilities; supportive care; person-centred care; multi-disciplinary care; palliative care; integrative review; organisational implications

Introduction

In the recent global action plan on the public health response to dementia 2017–2025, the World Health Organization (WHO, 2017: 2) describes dementia as ‘an umbrella term for several diseases that are mostly progressive, affecting memory, other cognitive abilities and behavior, and that interfere significantly with a person’s ability to maintain the activities of daily living’, configuring it as a public health priority. For many years, dementia care has been dominated by the standard medical approach (Katzman *et al.*, 1978), in which dementia is treated mainly with drugs, such as anti-anxiety, antidepressant and anti-psychotic medications (Bond,

1999; Sabat, 2008). The pervasive use of medications has often been accompanied by so-called malignant social psychology, a phrase coined by Kitwood (1990) for a style of interaction enacted by care-givers, which had the effect of depersonalising the treatment administered to persons with dementia. According to this approach, the loss of cognitive skills causes the loss of personhood (e.g. personal background, preferences, desires, interests, willpower); consequently, people with dementia have to be forced to execute daily self-care activities at prescheduled times¹ (Doyle and Rubinstein, 2013).

With the aim of seeking effective treatments for patients with dementia, over the last decades, a wide-ranging debate has emerged across different disciplines, such as psycho-gerontology, clinical gerontology, health economics and sociology of medicine. Within this framework, several authors have criticised the pervasive use of drugs for the management of behavioural and physiological symptoms related to dementia, showing how this kind of over-treatment can be both negative for the individual (Edge, 2009) and expansive for the collectivity (Glasziou *et al.*, 2013; Guzzon *et al.*, forthcoming). At the same time, other studies have shown that the behavioural symptoms of dementia (e.g. depression, anxiety, agitation, wandering) are partially due to brain damage and partially caused by the ways in which the person is treated by healthy people (Killick and Allan, 2001; Sabat, 2001; Wilkinson, 2002).

As an alternative to the standard medical approach, the concept of person-centred care has been proposed and developed by various authors (Kitwood and Bredin, 1992; Sabat and Harré, 1992; Kitwood, 1997, 1998; Sabat and Collins, 1999), in which good dementia care has to be built around the individual's needs and is contingent on knowing the person through an interpersonal relationship. The person-centred approach is rooted in the work of Tom Kitwood, who – along with Kathleen Bredin – suggests that dementia does not universally progress in a linear fashion, and most importantly, it varies from person to person (Kitwood and Bredin, 1992). At the same time, other works show that patients with significant cognitive impairments have manifestations of their identities, values and beliefs (Sabat and Harré, 1992; Jaworska, 1999; Sabat and Collins, 1999). More recently, starting from the principles of person-centred care, Hughes *et al.* (2009: 301) have used the concept of *supportive care*, intended as 'a full mixture of biomedical dementia care, with good quality, person-centred, psychosocial, and spiritual care under the umbrella of holistic palliative care throughout the course of the person's experience of dementia, from diagnosis until death'. With the concept of supportive care, the authors emphasise that person-centred care has to be extended throughout the course of the illness, guaranteeing the overall wellbeing of people with dementia and their relatives.

We conducted an integrative review addressing this research question:

- What are the organisational implications of supportive care interventions (SCIs) in long-term care facilities for people with dementia?

To answer this question, we focused on three interventions – person-centred, palliative and multi-disciplinary care – that play a key role in supporting people with dementia, according to Hughes and colleagues (Hughes *et al.*, 2009; Hughes, 2013). Although the clinical effects of SCIs on the health status of people with

dementia have been shown by various works, the organisational implications related to the implementation of these interventions are still under-investigated.

This paper is structured as follows. In the next two sections, we respectively introduce the notion of supportive care in dementia and show the methodology used in our literature review. We then focus on the results of our review, specifically the organisational implications of SCIs in long-term care organisations, regarding quality of care, care-givers' quality of life and cultural backgrounds. Finally, based on the presented results, we draw our conclusions.

Supportive care in dementia

Following the definition by the Organisation for Economic Co-operation and Development (2005), long-term care for older people can be described as support and care activities undertaken to ensure that people with loss of function and capacity are able to maintain their wellbeing. This can encompass care provided in the individual's own home or in an institutional setting (Milte *et al.*, 2019). In our work, we focus on the latter case, using the concept of long-term care facilities intended as 'nursing homes, skilled nursing facilities, and assisted living facilities ... [that] provide a variety of services, both medical and personal care, to people who are unable to manage independently in the community'.²

As Neil Henderson explains, in western societies, the placement of elderly people in long-term care organisations has been represented as a form of a *double burial* for a long time:

when a person is extracted from home because of dependencies that interrupt his or her ability, or his or her family's ability, to cope with the exigencies of life, the nursing home placement process becomes step one of a double burial ritual ... At this point, the sometimes lengthy step two of the double burial ritual begins. Rather than lie supine on the burial scaffold, as in some cultures, the patient languishes in long-term care parenthood until biological functions cease, at which time the second, and final, burial occurs. (Henderson, 2003: 154–155)

SCIs seem to challenge this representation of long-term care facilities for elderly people with dementia, strongly connected with the dominance of the standard medical approach, transforming these organisations in contexts where people with dementia are actively cared for and stimulated by competent professionals. The approach of supportive care has been previously experimented with in cancer care to address the patients' clinical and psycho-social needs in order to provide an optimal quality of life (Klasterky *et al.*, 2016). In cancer care, supportive care includes control of acute complications of the illness and/or its therapy, the management of pain and chronic complications, psycho-social and ethical-existential support once oncological therapy is no longer curative and, finally, the approach to the end of life (Carrieri *et al.*, 2018). Only in recent times have some works begun to apply this concept in dementia care (Hughes *et al.*, 2009; Hughes, 2013). As Hughes argues,

the point about supportive care is that, not only does it extend across the complete time course of the condition, not only is it intended to be broad in the sense of

biopsychosocial and spiritual, but – a practical level – nothing is ruled out and everything should be ruled in. (Hughes, 2013: 9)

Therefore, supportive care seems characterised by continuous support of patients and relatives from diagnosis until death, through a holistic approach to care and, finally, high flexibility in choosing the right care practices for each case. Starting from these considerations, it has been possible to individuate three key SCIs, which are at the core of our review.

First, ‘supportive care in dementia must be person-centred and, as such, it must be individual’ (Hughes *et al.*, 2009: 99). As suggested by Brooker (2003), the person-centred approach can be summarised by the acronym VIPS: *valu*ing people with dementia and their care-givers, treating them as *individuals*, adopting the *perspective* of the person with dementia and maintaining the person’s *social* environment because of the fundamental importance of relationships in sustaining personhood. From this perspective,

individuals need comfort or warmth to ‘remain in one piece’ when they may feel as though they are falling apart ... Individuals need to be socially included and involved both in care and in life [Pinkert *et al.*, *in press*], and more than simply being occupied; they need to be involved in past and current interests and sources of fulfilment and satisfaction. (Fazio *et al.*, 2018: 11)

Various reviews have underlined the following effects of the person-centred approach on resident outcomes: controlling the behavioural symptoms of residents, slowing their decline in the cognitive sphere and in activities of daily living, reducing the use of medication and defending their quality of life (Moos and Björn, 2006; Olsson *et al.*, 2013; Li and Porock, 2014).

Second, as the dementia progresses, the goals of care shift to include palliative care and remove much aggressive treatment from the care plan for patients (Brauner *et al.*, 2000). The diffusion of the person-centred care approach has affirmed the idea that people with dementia may be cared for and that care practices can improve their quality of life, also in the final stage of the illness. Palliative care in dementia is characterised by three key aspects: affirmation of life, encouraging people to live and, at the same time, to accept the inevitability of death; alleviating the distressing symptoms of whatever form and maintaining the quality of life; and a holistic approach during the end stages of dementia, assuring the biological, psychological, social and spiritual wellbeing of patients and their relatives (Hughes, 2013: 9). Various studies have shown how palliative care interventions have positive effects on patients with dementia, *e.g.* decreasing any observed discomfort (Volicer *et al.*, 1994), increasing the prescription of analgesia (Lloyd-Williams and Payne, 2002) and relieving delirium symptoms (Agar *et al.*, 2017).

Third, to meet patients’ and relatives’ needs, dementia care has to be provided by multi-disciplinary teams. Multi-disciplinary teams are crucial for paying attention to various dimensions, such as biological, psychological, social and spiritual aspects of care. As observed by Grand *et al.* (2011), team members often include professionals such as neurologists, geriatricians, neuropsychologists, nurses, physical therapists, occupational therapists and nutritionists. To assure continuity of care

throughout the course of the illness, professionals have to be co-ordinated by a key worker, appointed at the time of the diagnosis, who follows people with dementia and their relatives from the onset to the bereavement. In this case as well, the added value of a multi-disciplinary approach has been underlined by some reviews and studies on dimensions such as diagnostic accuracy (Wolfs *et al.*, 2006), cognitive impairments, functional deficits, and behavioural and psychological symptoms of dementia (Grand *et al.*, 2011).

As observed in cancer care, the implementation of SCIs seems to have several positive and critical organisational implications that practitioners have to take into account (Carrieri *et al.*, 2018). On one hand, these practices enrich care processes; on the other hand, they are often obstructed by infrastructural, professional and cultural barriers.

Method: an integrative review

To explore the organisational implications of supportive care in long-term care facilities for people with dementia, we conducted a review (1999–2019) focused on person-centred, palliative and multi-disciplinary care. We followed the integrative review method, which is specific and summarises past empirical or theoretical literature to provide a more comprehensive understanding of a particular phenomenon or health-care problem (Broome, 2000). This methodological approach includes five stages that guide the review design: (a) problem and purpose of the review identification; (b) literature search strategy description; (c) data and methodological quality evaluation; (d) data analysis, which includes data reduction, display, comparison and conclusions; and (e) presentation, which synthesises findings in a model that comprehensively portrays the integration process and describes the implications for practice, policy and research, as well as the limitations of the review (Whittemore and Knaff, 2005; Hopia *et al.*, 2016).

After identifying the problem (the organisational implications of supportive care in long-term care facilities for people with dementia), we began the study with an exploration of the literature addressing the implementation of supportive care in the residential setting. However, we soon realised that only a few studies have explicitly used the concept of supportive care in dementia. Consequently, we decided to redefine the scope of our review, individuating the key supportive care interventions and re-addressing the research around them. Our new aim was to analyse the organisational implications of supportive care interventions (*i.e.* person-centred, palliative and multi-disciplinary care) in long-term care facilities for people with dementia.

Search strategy and criteria for inclusion

Next, we defined our search strategy, identifying the inclusion and the exclusion criteria (Table 1). We searched published studies through the following databases: Google Scholar, PubMed and SAGE Journals. Electronic databases were searched using all combinations of the following keywords: dementia, long-term facilities, residential settings, person-centred care, palliative care, multi-disciplinary teams, evaluation, implementation and impact. With the aim of assuring the quality of

Table 1. Inclusion and exclusion criteria

<p>Articles had to be:</p> <ol style="list-style-type: none"> 1. Focused on older adults with dementia, living in long-term settings and adopting person-centred, palliative or multi-disciplinary care. 2. Focused on interventions aiming at changing the daily management of dementia. 3. Published between 1999 and 2019. 4. Peer-reviewed research articles in English. 5. Founded on empirical research.
<p>Articles should not be:</p> <ol style="list-style-type: none"> 1. Exclusively focused on patients. 2. Exclusively focused on clinical outputs. 3. Focused on interventions addressing elderly people living at home or in the community.

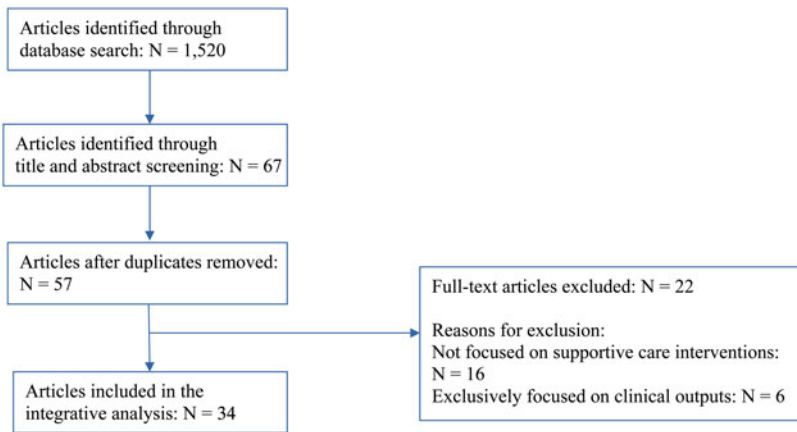


Figure 1. Procedure for the selection of studies.

selected papers, we restricted our search to empirical peer-reviewed research articles in English. We focused on articles published in academic journals because in journal articles, the knowledge about a specific topic is more consolidated compared with conference papers or book chapters. Afterwards, we screened selected papers – first, by abstract and second, by full text. A final sample of 34 articles was listed (see [Figure 1](#)).

Quality appraisal of included studies

Before beginning the in-depth analysis of the selected contributions, the quality appraisal was undertaken using the Critical Appraisal Skills Programme (2017), based on items relating to study design, data collection, data analysis and reporting of outcomes. Each article was awarded a quality rating of high, moderate or low, depending on the percentage of the answers that were coded as having met the criteria. The principal reviewer (FM) assessed the quality of all the articles, and the other three members of the research team (FN, GB and OP) checked for accuracy

within their subsets. Any disagreements were resolved through discussion or consultation. The quality appraisal was undertaken to aid in interpreting the findings and in determining the strength of the conclusions drawn; no study was excluded based on the results of the quality assessment.

Data collection and analysis

A content analysis (Schreier, 2012) of the articles that met the inclusion criteria was performed. A spreadsheet was used to summarise the main empirical findings of the articles. A subsequent comparison of the thematic segments led to the identification of interpretive categories through which the final analysis was conducted. The three conceptual categories included implications for care processes, implications for the quality of life of (formal and informal) care-givers and implications for cultural backgrounds.

Exploring supportive care interventions in dementia: person-centred, palliative and multi-disciplinary care

The review included 21 studies focused on the implementation of person-centred care, ten on palliative care and six on multi-disciplinary care (see Table 2). Three studies (Lloyd-Williams and Payne, 2002; Cleary and Doody, 2017; Zwijsen *et al.*, 2014) provided findings in more than one area and were therefore listed in more than one SCI. We considered 21 quantitative, eight qualitative and five mixed-method studies. As for their geographical spread and settings, the studies were conducted primarily in the United States of America (USA) (N = 8), the Netherlands (N = 8), the United Kingdom (UK) (N = 7) and Australia (N = 6), with the remainder undertaken in Canada (N = 3), Sweden (N = 1) and Ireland (N = 1). Regarding the sample, 23 studies gathered data only about staff members, six only about patients, three about staff and patients and two about staff, patients and relatives.

Person-centred care

The first strand of the contributions pays attention to the effects of person-centred care (and of associated training programmes) on various organisational dimensions in long-term care facilities, such as the quality of provided care, the quality of work of formal care-givers, the professional skills of managers and workers, and the organisational cultures.

First, a significant number of the considered studies also focus on the consequences of person-centred models on care processes. Person-centred care improves the number of interactions and the attitude of the personnel towards elderly people and increases the flexibility in care regimes (Fritsch *et al.*, 2009; Chenoweth *et al.*, 2015), as well as the communication skills of professionals (Ashburner *et al.*, 2004; Passalacqua and Harwood, 2012) and continuity of care (Berkhout *et al.*, 2004; Boumans *et al.*, 2005). From the staff's perspective, these changes are vital to ensure that the individuals' needs are met (Cleary and Doody, 2017). Moreover, except for the study conducted by Boumans *et al.* (2005), there is consensus that

Table 2. Details of the studies included in the review

Author, year	Country	Title of the article	Supportive care practice	Design (D), data collection (Da) and number of participants (N)	Organisational implications
Abendstern <i>et al.</i> , 2006	UK	Levels of integration and specialisation within professional community teams for people with dementia	Multi-disciplinary care	D: Quantitative cross-sectional postal survey. Da: Postal survey. N: 52 teams	Multi-disciplinary teams are more likely than single-discipline teams to offer a specialised and integrated service. Single-discipline teams are more likely to offer a culturally sensitive service.
Amador <i>et al.</i> , 2016	UK	Evaluation of an organisational intervention to promote integrated working between health services and care homes in the delivery of end-of-life care for people with dementia: understanding the change process using a social identity approach	Multi-disciplinary care	D: Qualitative action research. Da: Facilitated meetings, interviews. N: 3 teams (20 professionals)	The introduction of the multi-disciplinary team approach assures high quality of care. Facilitating meetings among professionals can encourage the recognition of a shared social identity and of similar goals and values.
Andersson <i>et al.</i> , 2017	Sweden	End-of-life care in residential care homes: a retrospective study of the perspectives of family members using the VOICES questionnaire	Palliative care	D: Quantitative survey. Da: Questionnaire about quality of care. N: 183 relatives of dying patients	This study indicates that the quality of care in residential settings is high. Inadequate management is found for symptom relief on the last days of life. This suggests that this subject merits further attention by care professionals.

Ashburner <i>et al.</i> , 2004	UK	Using action research to address loss of personhood in a continuing care setting	Person-centred care	D: Quasi-experimental mixed-method study. Da: Resident biographies; interviews with staff, residents and family; quality interaction schedule. N: 46 nurses	The study focuses on the introduction of a person-centred care approach supported by specific actions (e.g. the collection and sharing of residents' life histories, weekly team supervision meetings for staff). The considered organisational innovation increases staff confidence in providing person-centred care.
Berkhout <i>et al.</i> , 2004	Netherlands	Resident-oriented care in nursing homes: effects on nurses	Person-centred care	D: Quasi-experimental mixed-method study. Da: Written surveys, semi-structured interviews, residents' files, methodical nursing scale. N: 210 nurses	In the intervention, each patient is assigned to a primary nurse who becomes responsible for the total nursing care of patients. After the implementation, the quantitative data show that in experimental groups, residents are assigned more frequently to the same nurse. The qualitative data show that the planned delegation of co-ordination tasks to primary nurses is not fully achieved.
Boumans <i>et al.</i> , 2005	Netherlands	Effects of resident-oriented care on quality of care, wellbeing and satisfaction with care	Person-centred care	D: Quasi-experimental quantitative study. Da: Written survey. N: 286 nurses	The intervention is partly successful in the intervention group. Some aspects of the resident-oriented care

(Continued)

Table 2. (Continued.)

Author, year	Country	Title of the article	Supportive care practice	Design (D), data collection (Da) and number of participants (N)	Organisational implications
					model are not clearly evident. Moreover, the effects on quality-of-care aspects are limited. The results reveal the increase in the 'co-ordination of care' on half of the experimental wards.
Brandt <i>et al.</i> , 2005	Netherlands	The last days of life of nursing home patients with and without dementia assessed with the palliative care outcome scale	Palliative care	D: Quantitative observational cohort study. Da: Questionnaire on basic demographics, illness characteristics (e.g. stage of dementia), symptoms, direct cause. N: 32 patients in terminal phase	The study demonstrates that most of the patients are considered terminally ill only when death is already very near. According to the authors, it is more difficult to provide appropriate palliative care for elderly patients with chronic diseases than for patients with cancer.
Campbell and Guzman, 2004	USA	A proactive approach to improve end-of-life care in a medical intensive care unit for patients with terminal dementia	Palliative care	D: Quantitative observational cohort study. Da: Retrospective chart review. N: 52 patients with end-stage dementia	The study compares the usual care with a proactive case-finding approach for critically ill patients with terminal dementia using an inpatient palliative care service. The proactive palliative intervention decreases the time between the identification of the poor prognosis and the establishment of clinical goals.

Chenoweth <i>et al.</i> , 2015	Australia	PerCEN trial participant perspectives on the implementation and outcomes of person-centered dementia care and environments	Person-centred care	D: Qualitative participatory action research. Da: Semi-structured interviews with staff, telephone surveys with family members, staff reports of care approaches, field note entries recorded by facilitators. N: 29 care managers, 70 nurses and care staff	From the perspectives of the staff and relatives, person-centred care increases the number and variety of opportunities for resident interaction, the flexibility in care regimens and the staff's attention to resident needs.
Cleary and Doody, 2017	Ireland	Nurses' experience of caring for people with intellectual disability and dementia	Person-centred care, multi-disciplinary care	D: Qualitative Husserlian descriptive phenomenological methodology. Da: Interviews. N: 11 nurses	From the nurses' perspective, the person-centred approach is vital to ensure that the individuals' needs are met. The participants view the role of the multi-disciplinary team positively as a decision-making forum and for developing plans for persons with challenging behaviours.
Diwan <i>et al.</i> , 2004	USA	Strain experienced by caregivers of dementia patients receiving palliative care: findings from the Palliative Excellence in Alzheimer Care Efforts (PEACE) Program	Palliative care	D: Qualitative study. Da: Structured interviews with care-givers; Caregiver Strain Index. N: 150 patient-care-giver dyads	Although through palliative care, patients' wellbeing improves, care-givers continue to experience significant stress when three kinds of strain are assessed: adjustment or role strain, personal strain and emotional strain.

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Table 2. (Continued.)

Author, year	Country	Title of the article	Supportive care practice	Design (D), data collection (Da) and number of participants (N)	Organisational implications
Doyle and Rubinstein, 2013	USA	Person-centered dementia care and the cultural matrix of othering	Person-centred care	D: Ethnography. Da: Participant observation and ethnographic interviews with staff members (nurses and aides) and patients. N: 20 people with dementia and 25 staff members	The study shows how after the introduction of the person-centred model, the biomedical model of dementia still persists. 'New' and 'old' models of care co-exist and are intertwined. The more traditional approaches to dementia care (task completion and biomedical focus) still dominate in the considered organisations. The data suggest that even 'normal' behaviours (e.g. walking) are often interpreted as a result of a 'dementing' process.
Edvardsson <i>et al.</i> , 2011	Australia	Job satisfaction amongst aged care staff: exploring the influence of person-centered care provision	Person-centred care	D: Quantitative study. Da: Job satisfaction and the person-centred care assessment tool. N: 297 residential aged-care staff	Person-centred care can enhance job satisfaction and staff retention.
Edvardsson <i>et al.</i> , 2014	Australia	Implementing national guidelines for person-centered care of people with dementia in residential aged care: effects on perceived	Person-centred care	D: Quasi-experimental quantitative study. Da: Questionnaire about the perceived provision of person-centred care at the facility and job	The intervention results in significantly higher scores on the person-centredness of care at follow-up, and the facility is rated as being significantly more

		person-centeredness, staff strain, and stress of conscience		satisfaction. N: 171 staff members (nurse aides and health-care professionals)	hospitable at follow-up. A significant reduction in staff stress of conscience is also found at follow-up.
Finnema <i>et al.</i> , 2005	Netherlands	The effect of integrated emotion-oriented care versus usual care on elderly persons with dementia in the nursing home and on nursing assistants: a randomized clinical trial	Person-centred care	D: Randomised controlled trial. Da: Stress scale. N: 99 nursing assistants	Positive significant differences in stress reduction are observed in favour of the intervention group.
Fritsch <i>et al.</i> , 2009	USA	Impact of TimeSlips, a creative expression intervention program, on nursing home residents with dementia and their caregivers	Person-centred care	D: Randomised controlled trial. Da: Structured observations of staff-resident interactions, burnout and job satisfaction scales. N: 192 staff members	In experimental facilities, there are more frequent staff-resident interactions. The staff members who have participated in the experimental programme also hold more positive views of residents with dementia and devalued residents less than the control group staff members do. No significant results are observed for job satisfaction and burnout.

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Table 2. (Continued.)

Author, year	Country	Title of the article	Supportive care practice	Design (D), data collection (Da) and number of participants (N)	Organisational implications
Hockley <i>et al.</i> , 2005	UK	Promoting end-of-life care in nursing homes using an 'integrated care pathway for the last days of life'	Palliative care	D: Mixed-method action research. Da: Document analysis, participant observation, interviews with relatives, culture and organisation of care questionnaire. N: 16 nurse-patient dyads	The purpose of this study is to promote quality end-of-life care in nursing homes using an 'integrated care pathway (ICP) for the last days of life' document. With the study's progress, there is an increasing realisation of an overarching pattern emerging around care given to residents on the last days of their lives, that is, dying is becoming more central to nursing home work and less on the periphery.
Jeon <i>et al.</i> , 2012	Australia	Staff outcomes from the caring for aged dementia care resident study (CADRES): a cluster randomised trial	Person-centred care	D: Randomised controlled trial. Da: Burnout and stress scales. N: 124 nurses and nursing assistants	Significant decreases in emotional exhaustion are observed. There is no significant decrease in depersonalisation in both intervention groups. A significant time effect on stress is found, which increases at post-intervention but declines at follow-up.

Kolanowski <i>et al.</i> , 2015	USA	'Wish we would have known that!' Communication breakdown impedes person-centered care	Person-centred care	D: Qualitative study. Da: Focus groups. N: 59 staff members (79% nurses, 21% others)	Resident information is not routinely shared with all staff, and written documentation systems for communicating resident-specific information do not support the time-pressured work pattern of certified nursing assistants. From the staff's perspective, these factors seem to obstruct the delivery of person-centred care.
Lloyd-Williams and Payne, 2002	UK	Can multidisciplinary guidelines improve the palliation of symptoms in the terminal phase of dementia?	Palliative care, multi-disciplinary care	D: Quantitative retrospective study. Da: Medication cards and case notes. N: 27 patients	The study suggests that guidelines developed by a multi-disciplinary team can improve palliative care in a setting where it may not previously have been recognised or practised. The notes and direct observations of practices on the ward suggest that the nurses have developed a very intimate caring relationship with their patients, are able to calm the patients and are also very sensitive to any changes in their behaviours.

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Table 2. (Continued.)

Author, year	Country	Title of the article	Supportive care practice	Design (D), data collection (Da) and number of participants (N)	Organisational implications
Mezey <i>et al.</i> , 2000	Canada	Effects of an abilities-focused program of morning care on residents who have dementia and on caregivers	Person-centred care	D: Quasi-experimental quantitative study. Da: Scales for measuring behaviours of elderly residents, ease of care-giving and level of stress. N: 40 residents and 44 nursing staff members	A significant treatment effect in favour of the experimental group is found on time pressure, perceived problems, stress reactions and emotional exhaustion. The nursing assistants in the experimental group also improve their overall job satisfaction score. In particular, they are more satisfied with the quality of care and with their contact with the residents.
Minkman <i>et al.</i> , 2009	Netherlands	Integrated dementia care in The Netherlands: a multiple case study of case management programmes	Multi-disciplinary care	D: Qualitative multiple case study. Da: Semi-structured interviews. N: 16 responsible managers and case managers	The study considers eight local dementia care networks. Care networks achieve their goals when there is a case manager with expert knowledge and good personal connections with the medical staff. Moreover, the involvement of primary care specialists in the care network seems crucial.

Mitchell <i>et al.</i> , 2004	USA	Dying with advanced dementia in the nursing home	Palliative care	D: Quantitative comparative analysis between residents with advanced dementia and residents with terminal cancer. Da: Minimum data-set. N: 1,784 patients with dementia and 918 patients with cancer	The authors point out that nursing home residents dying with advanced dementia are not perceived as having a terminal condition, and most do not receive optimal palliative care. Management and educational strategies are needed to improve end-of-life care in advanced dementia.
Passalacqua and Harwood, 2012	USA	VIPS communication skills training for paraprofessional dementia caregivers: an intervention to increase person-centered dementia care	Person-centred care	D: Quasi-experimental quantitative study. Da: Emotional exhaustion and depersonalisation scales N: 26 direct care workers	There are positive significant differences in the decrease in depersonalisation of residents and an increase in both empathy and hope for those with dementia. Additionally, care-givers report using more concrete communication strategies that are known to be effective for those who suffer from dementia.
Roberts <i>et al.</i> , 2015	Australia	Caring for people with dementia in residential aged care: successes with a composite person-centered care model featuring Montessori-based activities	Person-centred care	D: Quasi-experimental mixed-method study. Da: audit of medication charts, CMAI (Cohen-Mansfield Agitation Inventory) score and Cognitive Impairment scale, TURNIP scale for analysing staff's	In organisations that adopted the new model the study has observed reduction of medication prescription and verbally agitated behaviours. Moreover, experimental groups were characterised by an improvement of

(Continued)

Table 2. (Continued.)

Author, year	Country	Title of the article	Supportive care practice	Design (D), data collection (Da) and number of participants (N)	Organisational implications
				perceptions about care environment, qualitative interviews for family carers. N: 15 patients, 15 families, 13 staff members (nurses and personal care attendants)	quality of care, quality of life and by positive relatives' representations.
Robinson and Rosher, 2006	USA	Tangling with the barriers to culture change: creating a resident-centered nursing home environment	Person-centred care	D: Quantitative study. Da: Family questionnaires, quality of work-life questionnaires. N: 151 staff members	After a two-year implementation phase of the person-centred model at the facility, family satisfaction has increased, and the staff members indicate a higher purpose and meaning to their job. However, the staff do not feel more involved in decision making within the organisation.
Ryan <i>et al.</i> , 2012	UK	Barriers and facilitators to the receipt of palliative care for people with dementia: the views of medical and nursing staff	Palliative care	D: Qualitative study. Da: Focus groups and individual interviews. N: 58 palliative care practitioners	The barriers to timely and appropriate transitions to palliative care for people with dementia and their families are still strong. The paper concludes with recommendations for policy and practice development.

Sampson <i>et al.</i> , 2006	UK	Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study	Palliative care	D: Quantitative retrospective study. Da: Medication cards and case notes. N: 122 cases of deceased patients	People with dementia receive significantly less palliative medication or referrals to palliative care teams prior to death. In these patients, less attention is paid to their spiritual needs and religious backgrounds.
Savundranayagam, 2014	Canada	Missed opportunities for person-centered communication: implications for staff-resident interactions in long-term care	Person-centred care	D: Quantitative study. Da: Recorded conversations between staff and residents. N: 13 staff-resident dyads	The findings reveal a common communication sequence where utterances coded as person-centred are followed by utterances coded as missed opportunities. This sequence suggests that the positive impact of person-centred communication may be undermined when such communication is followed by missed opportunities.
Schrijnemaekers <i>et al.</i> , 2003	Netherlands	Effects of emotion-oriented care on work-related outcomes of professional caregivers in homes for elderly persons	Person-centred care	D: Randomised controlled trial. Da: Scales for job satisfaction and burnout. N: 300 professional care-givers (nursing assistants and geriatric assistant nurses)	Short-term differences are observed in favour of the intervention group. The differences are statistically significant for two sub-scales of job satisfaction (opportunities for self-actualisation and contact with residents) and one sub-scale of burnout (personal

(Continued)

Table 2. (Continued.)

Author, year	Country	Title of the article	Supportive care practice	Design (D), data collection (Da) and number of participants (N)	Organisational implications
Silvester <i>et al.</i> , 2013	Australia	Quality of advance care planning policy and practice in residential aged care facilities in Australia	Palliative care	D: Quantitative survey. Da: Questionnaires about implementation of palliative care policies. N: 45 staff members of a residential care home	accomplishment). The findings are not consistent over time. The implementation of existing policies and procedures is limited. The quality of existing documentation is poor. The staff members of the residential care facilities have relatively limited experience in developing advanced care plans with the residents, although the attitudes are positive.
Van Weert <i>et al.</i> , 2005	Netherlands	The effects of the implementation of snoezelen on the quality of working life in psychogeriatric care	Person-centred care	D: Randomised controlled trial. Da: Job satisfaction, stress and burnout scales. N: 300 staff members	Positive significant differences are observed in favour of the intervention group regarding satisfaction with the quality of care, contact with residents, stress level, burnout and total job satisfaction.
Viau-Guay <i>et al.</i> , 2012	Canada	Person-centered care training in long-term care settings: usefulness and facility of transfer into practice	Person-centred care	D: Quantitative study. Da: Open-ended questionnaires. N: 392 trained care-givers (nurses, nurses' assistants, occupational	The barriers of the relationship-centred care at the facility include lack of training, personal factors, such as reluctance to change or belief in the

Zwijzen <i>et al.</i> , 2014	Netherlands	Coming to grips with challenging behavior: a cluster randomized controlled trial on the effects of a multidisciplinary care program for challenging behavior in dementia	Multi-disciplinary care, person-centred care	therapists, physiotherapists and recreation technicians) D: Randomised controlled trial. Da: Assessment of challenging behaviour and medications, interviews. N: 659 residents and 16 staff members	medical model of care, and resident and family characteristics. The resident group that remains in the intervention condition, compared with the control group, decreases significantly in challenging behaviours. The staff members globally appreciate the considered organisational change.
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Notes: UK: United Kingdom. USA: United States of America.

person-centred care increases the quality of care, with particular reference to the following dimensions: staff's and families' satisfaction with the quality of care (Van Weert *et al.*, 2005; Robinson and Rosher, 2006; Edvardsson *et al.*, 2014; Roberts *et al.*, 2015) and the ability to involve relatives in decisions concerning their relatives (Chenoweth *et al.*, 2015). However, during the implementation of person-centred care models, some critical issues arise. Kolanowski *et al.* (2015) point out that time constraints, as well as lack of sufficient staff and of information systems to support information exchange, obstruct person-centred care. In particular, in this study conducted in the USA, the staff members identify the unmet need for access to the residents' psycho-social/medical histories and the knowledge of the strategies that the families used for managing behavioural symptoms in the past. In research carried out in Canada, Savundranayagam (2014) shows that during the interactions between the staff and the residents, utterances coded as person-centred (e.g. calling the resident by name, asking about his or her desires and preferences) are followed by utterances coded as missed opportunities (*i.e.* instances where person-centred communication strategies could have been used to preserve and/or enhance a resident's sense of self). The author suggests that the positive impact of person-centred communication may be undermined when followed by missed opportunities.

Second, much research pays attention to the effects of person-centred care on the quality of work. The implementation of person-centred care models seems to have positive effects on job satisfaction (Schrijnemaekers *et al.*, 2003; Van Weert *et al.*, 2005; Robinson and Rosher, 2006; Edvardsson *et al.*, 2011). Taking into consideration staff in Australian residential aged-care facilities, Edvardsson *et al.* (2011) show that staff perception of the provision of person-centred care is associated with increased personal satisfaction, as well as the awareness of having a more balanced workload and receiving more professional support. According to the authors, this happens because with person-centred care, there is an increment of self-perceived personal and professional growth, feelings of worthwhile accomplishments and perceived quality of work. Two studies (Berkhout *et al.*, 2004; Fritsch *et al.*, 2009) find no difference in the job satisfaction between experimental groups (*i.e.* staff members who work in facilities that adopt person-centred care) and control groups. Other works show how person-centred care reduces staff stress and, in particular, time pressure, perceived problems, stress reactions and emotional exhaustion (Mezey *et al.*, 2000; Finnema *et al.*, 2005; Edvardsson *et al.*, 2014). In this respect, Jeon *et al.* (2012) point out that significant effects of stress decline at follow-up. The overall improvement of the quality of work seems to have positive effects in terms of decreasing sick leave (Berkhout *et al.*, 2004) and increasing staff retention (Edvardsson *et al.*, 2011).

Finally, as well known, organisational change is often accompanied by conflicts. As underlined by some studies (Viau-Guay *et al.*, 2013; Doyle and Rubinstein, 2013), person-centred care promotes a culture of care that can radically differ from the pre-existing cultural assumptions and beliefs about dementia, often related to the so-called medical standard care. In their ethnographic study of an American long-term care organisation, Doyle and Rubinstein (2013) investigate the ways in which pre-existing organisational practices and cultural backgrounds can obstruct organisational change. The authors show how, during the transition period,

Table 3. Person-centred care and organisational implications

	Positive implications	Critical implications
Care processes	<ul style="list-style-type: none"> • Higher overall quality of care for patients with dementia • More interactions between staff and residents • More flexibility in care regimes • More continuity of care • Improvement of staff communication skills • Staff and families' higher satisfaction with quality of care • More family involvement 	<ul style="list-style-type: none"> • Complications for information exchange • Alternating between person-centred and non-person-centred interactions
Quality of life of care-givers	<ul style="list-style-type: none"> • More job satisfaction • Less staff stress • Less sick leave • Less staff retention 	<ul style="list-style-type: none"> • No effects on job satisfaction • Only temporary effects on staff stress
Cultural backgrounds	<ul style="list-style-type: none"> • Less depersonalisation 	<ul style="list-style-type: none"> • No effects on depersonalisation • Conflicts between person-centred culture and pre-existing cultural backgrounds

practices inspired by person-centred care become interwoven with 'standard' practices characterised by depersonalising patients with dementia. Changing beliefs and assumptions about dementia – and, consequently, patient care practices – seems a huge challenge that can be overcome only by enacting specific strategies (e.g. increasing the social engagement between the residents and the staff members).

Palliative care

Although the symptoms experienced in the last year of life by people with dementia and by cancer patients are comparable (see McCarthy *et al.*, 1997), e.g. in terms of experienced pain and loss of appetite, patients with dementia are at particular risk of receiving poor end-of-life care.

Most of the studies focused on the application of palliative care in dementia assess the care processes and their quality, often in comparison to the palliative care provided to patients with other diseases. Various studies note how patients with dementia may be receiving different end-of-life care from that received by patients who are cognitively intact (Mitchell *et al.*, 2004; Brandt *et al.*, 2005; Sampson *et al.*, 2006). Older people receive significantly less palliative medication prior to death; most patients are not recognised as dying, hospice referrals are infrequent (Mitchell *et al.*, 2004) and symptom relief is inadequately managed (Andersson *et al.*, 2017). In patients where dementia is noted, less attention is paid to their psycho-social and spiritual needs and religious backgrounds

Table 4. Palliative care and organisational implications

	Positive implications	Critical implications
Care processes	<ul style="list-style-type: none"> • Higher overall quality of care for patients with dementia • Dedicated organisational programmes can further improve the quality of palliative care (reducing critical implications) 	<ul style="list-style-type: none"> • Palliative care is still less accessible for people with dementia • The staff members pay little attention to the psycho-social and the spiritual needs of patients with dementia • National guidelines are insufficient
Quality of life of care-givers	–	<ul style="list-style-type: none"> • Palliative care does not decrease familiar care-givers' stress
Cultural backgrounds	–	<ul style="list-style-type: none"> • The staff members often perceive dementia as a non-fatal disease • The staff members consider themselves unsuitable for interacting with people with dementia

(Brandt *et al.*, 2005; Sampson *et al.*, 2006). According to the two last cited groups of authors, patients with dementia can be assisted in non-physical aspects empowering non-verbal communication. As reported by some of the reviewed literature (Lloyd-Williams and Payne, 2002; Campbell and Guzman, 2004; Brandt *et al.*, 2005; Hockley *et al.*, 2005), improving the quality of palliative care requires implementing dedicated programmes in residential facilities. If not supported by organisational change processes, national guidelines risk being insufficient (Silvester *et al.*, 2013).

Other works consider the effects of palliative care aimed at improving the quality of life of people with dementia and their relatives (*e.g.* Lloyd-Williams and Payne, 2002). They show how such interventions improve various aspects of the quality of care (*e.g.* pain control and more appropriate attention to patients' previously stated wishes). In a qualitative study carried out in the USA, Diwan *et al.* (2004) note that although patients' wellbeing improves, care-givers continue to experience significant stress when three kinds of strain are assessed: adjustment or role strain (*i.e.* work adjustment, family adjustments, change in personal plans and other demands on time), personal strain (*i.e.* physical strain, financial strain, sleep disturbance, feeling confined and feeling overwhelmed) and emotional strain (*i.e.* being upset because the patient has changed, the patient's behaviours are upsetting and emotional adjustment). Patient problem behaviours and functional limitations, perceived lack of support from the health-care team and higher socio-economic status are predictors of care-giver strain. The authors suggest that it is necessary

to develop effective programmes that offer meaningful end-of-life support and care for both patients with dementia and their families.

If it is well known that the needs of patients with dementia and their relatives are often underestimated by health-care professionals, less attention has been paid to the reasons behind this attitude. Through a qualitative study conducted in the UK, Ryan *et al.* (2012) explore the role played by professionals in either facilitating or obstructing the transition to palliative care for people with dementia. The research suggests that considerable difficulties remain in the achievement of good-quality end-of-life care in the form of palliative services for people with dementia. First of all, health-care practitioners often do not perceive people with dementia as candidates for palliative care for many reasons. For some study participants, the idea that dementia constitutes a condition that can be a cause of death is questionable. Dementia is sometimes interpreted as a normal pathological aspect of ageing rather than a specific illness; other 'conditions' are considered worthy of specialist palliative care, in contrast to dementia. Moreover, health-care professionals recognise that current skills and competencies within health-care teams are insufficient to assess the needs of people with dementia. In particular, for the participants, it is problematic to work with a group of people who find it difficult to communicate their needs. Consequently, in an uncertain context, professionals often have recourse to pharmaceutical, rather than behavioural, interventions. Finally, the team members suggest that to enhance the quality of provided care, it is necessary to co-operate with other specialists in the field of dementia care.

Multi-disciplinary care

The third strand of the contributions focuses on the consequences of multi-disciplinary care in long-term care facilities on organisational dimensions, such as the quality of provided care, the integration of the skills of different professionals and the interaction among the involved professional backgrounds.

First, all considered contributions highlight how a multi-disciplinary approach improves the quality of care from various perspectives, focusing mostly on emerging representations in professionals and in relatives. In their survey of professional teams in North-West England (UK), Abendstern *et al.* (2006) underline how multi-disciplinary teams are more suitable than single disciplinary teams for providing person-centred care, reaching a high integration with other services (*e.g.* general practitioner (GP) services, primary health services and other local dementia agencies) and assessing and tailoring in depth the needs of patients with dementia. The authors do not find particular differences in the capability of continuously involving care-givers in the development of care processes. Similarly, Cleary and Doody (2017) explore Irish nurses' experience in caring for patients with dementia and emphasise how collaboration among professionals with different areas of expertise can be vital for making the 'right decision', carefully assessing and supporting the behaviours of people with dementia and, finally, providing person-centred care. Minkman *et al.* (2009) report positive reactions by elderly people and their familial care-givers to the quality of received services, particularly in terms of service delays and stress among care-givers. Moreover, in the Netherlands, Zwijsen *et al.* (2014) show how a multi-disciplinary care programme leads to a decrease in challenging

Table 5. Multi-disciplinary care and organisational implications

	Positive implications	Critical implications
Care processes	<ul style="list-style-type: none"> • Higher overall quality of care for patients with dementia • Easier to make the ‘right’ decision • Greater control over challenging behaviours • Reduction in service delays • More integration of knowledge and backgrounds of various professionals 	<ul style="list-style-type: none"> • Fragmentation of dementia care services (avoidable through the support of case managers) • Programmes have to be adjusted to the daily routine of each organisation
Quality of life of care-givers	<ul style="list-style-type: none"> • Less stress among familiar care-givers 	–
Cultural backgrounds	–	<ul style="list-style-type: none"> • Conflicts among different professional cultures (avoidable through dedicated organisational interventions)

behaviour and in the prescription of psychoactive drugs without an increase in the use of restraints. Thanks to this programme, the focus on care-giving for people with dementia has gradually evolved from a pure disease-oriented view to a more person-centred and tailored approach, reaching a high consensus among professionals. The authors note as a critical point that to achieve the desired effects, the programme has to be adjusted to the daily routine of each nursing home involved in the study, increasing the risk of implementation problems.

Multi-disciplinary teams are generally created to integrate the knowledge and the backgrounds of various professionals. However, multi-disciplinary teams can be characterised by numerous conflicts among different professional cultures. Nonetheless, Amador *et al.* (2016) show that when supported by dedicated intervention, in English care homes, professionals with different backgrounds (*i.e.* staff and visiting health-care practitioners, such as GPs and district nurses) have developed a shared social identity rooted in common values and goals in the field of dementia care. For example, end-of-life management is particularly crucial for all involved professionals who (through continuous meetings) construct a common strategy for caring for residents and interacting with family members. Moreover, this study shows that by sharing common goals and values, health-care professionals with different backgrounds can find innovative solutions for improving care processes. The fragmentation of dementia care services can also be overcome with the support of specific co-ordinators. In a qualitative study conducted in the Netherlands, Minkman *et al.* (2009) show that case managers can play a crucial role in connecting different health-care organisations, such as nursing homes, mental health services, Alzheimer associations and patient associations. The authors report that in the face of the increasing numbers of elderly people with

dementia, case managers carry out the following activities that are vital for providing client-tailored services: care assessment, care planning, co-ordination of tasks, implementation and evaluation of programmes, and emotional and practical support for patients and their relatives. In this framework, case managers are professionals who should assure continuity among different spheres of care (*i.e.* primary, specialty, mental and long-term health care).

Discussion

Over the last decades, an inter-disciplinary debate has emerged around dementia care, providing theoretical and practical tools that are useful for overcoming the standard medical approach and the so-called malignant social psychology. In our work, we have focused on three SCIs (*i.e.* person-centred, palliative and multi-disciplinary care) that play a key role in assisting people with dementia and their relatives during the illness trajectory (Hughes *et al.*, 2009). In particular, we have conducted a literature review with the aim of exploring the positive and critical implications of the implementation of SCIs for long-term care organisations. Our analysis points out that each SCI has consequences for care processes, the quality of life of care-givers and cultural backgrounds. This detailed analysis (summarised in Tables 3–5) leads to three main considerations concerning the implications of SCIs for long-term care organisations.

First, a still limited number of contributions explore the conflict dynamics between SCIs and pre-existing cultural backgrounds, intended as values and beliefs that provide norms of expected behaviours that people might follow (Schein, 1991). The beliefs concerning dementia (*e.g.* as an illness that causes the loss of personhood and/or that is less painful than other degenerative diseases) underpin the behaviours that can obstruct the introduction of a new practice (*e.g.* not providing palliative care to residents with dementia) or change the course of its implementation (*e.g.* producing a care process in which person-centred care is interwoven with standard medical care). In the case of multi-disciplinary teamwork, the implementation of the new interventions is obstructed by the existing discrepancies among the involved professional cultures; each profession is characterised by a well-defined identity and values that can prevent inter-disciplinary co-operation (Hall, 2005). Therefore, pre-existing cultural backgrounds seem to affect the implementation of SCIs, leading to unexpected and unwanted results. If the ‘betrayal’ of an innovative idea is well known in organisation studies (Czarniawska-Joerges and Sevón, 2005), in this case, it prevents, at least partially, the improvement of the wellbeing of the members of the considered organisations.

Second, for supporting the changes in care processes and cultural backgrounds, several works underline the importance of advanced training programmes. Most of the person-centred care literature focuses on person-centred models that have been flanked by training programmes addressed to personnel, with particular reference to nursing home staff. The growing attention paid by international and national institutions to the dementia-related knowledge gaps (Hughes *et al.*, 2008) seems to be followed by specific organisational programmes directed to the workforce. Probably also for this reason, the implementation of person-centred care practices seems to have several positive implications in long-term care facilities. Although

some studies (Doyle and Rubinstein, 2013; Viau-Guay *et al.*, 2013) emphasise that the cultural backgrounds underpinning the actions of professionals seem to incorporate new and old beliefs about dementia, this mixture does not appear to prevent a substantial shift in care processes and care-givers' quality of life. In the other considered SCIs, the educational programmes remain rare. In particular, the lack of education for staff in palliative care, previously revealed by various works (*e.g.* Chang *et al.*, 2005), seems to have serious negative consequences on the quality of care that is often low due to the lack of attention to both physical and non-physical needs of people with dementia.

Finally, a methodological consideration is needed. The dominance of quantitative studies has influenced the results of our review, at least in two ways. On one hand, more attention is paid to the outputs of the implementation of SCIs than to the ways in which the new care models are implemented. Consequently, the reasons that underpin the success or the failure of the implementation processes are often under-investigated. For example, although the key role of cultural backgrounds in either facilitating or obstructing health-care innovations is well known (Carrieri *et al.*, 2018), in the considered literature, the attention paid to this aspect is still limited. On the other hand, the emerging results of the selected studies are often strictly connected to the expectations of the authors and of the designers of the considered innovations. Tools such as validated scales are chosen with the aim of measuring the degree to which the expected effects have been achieved, and other kinds of outcomes are rarely considered (*e.g.* in the literature concerning palliative care, the consequences on formal care-givers' stress have not been taken into consideration). A greater usage of qualitative techniques (and in particular, of ethnography and unstructured interviews) could increase the focus on the unexpected effects of new care interventions.

Implications for practice and science

The current review leads to a better understanding of the organisational implications derived from the implementation of person-centred, palliative and multi-disciplinary care. As explained above, we have chosen these interventions because they have been previously indicated as care approaches that play a key role in guaranteeing the holistic wellbeing of people with dementia and their relatives. In particular, our work underlines the positive effects of SCIs on organisations and care-givers, at the same time focusing on the critical implications related to the introduction of the considered care interventions. In our opinion, this study provides an actual overview that can be useful for managers and health-care professionals employed in organisations that are considering whether or not to implement these interventions. Moreover, the knowledge established in this review can be used by long-term care facility managers for planning the implementation of SCIs in their organisations and for facing the possible emerging challenges (*e.g.* defining training courses for the staff to change the pre-existing cultural assumptions about dementia and palliative care).

Our work also highlights the knowledge gaps in current research about SCIs and organisational implications. First, our work points out that the literature about person-centred care in long-term care organisations is much more developed

than the studies on other care approaches. There are multiple reasons for these differences. On one hand, the advancement of research concerning the organisational implications of palliative care has often been limited by complex ethical issues (Sampson, 2010) and by the high degree of attention paid to clinical outcomes (Sampson *et al.*, 2005; Robinson *et al.*, 2012). On the other hand, in the case of multi-disciplinary care, the literature has paid more attention to community care programmes than to interventions carried out in long-term organisations (Thomas, 2010; Bieber *et al.*, 2018). Second, in the debates about palliative care and multi-disciplinary care, more attention is needed regarding the quality of life of formal care-givers. For example, in cancer care, staff stress in a multi-disciplinary team (Ekedahl and Wengström, 2008) and in palliative care (Vachon, 1999; Dougherty *et al.*, 2009; Pfaff and Markaki, 2017) has been analysed in depth. Third, as already highlighted, it is necessary to focus on the interaction between organisational and professional cultural backgrounds and new interventions.

Notes

1 Here, we neither discuss nor review the literature concerning the supposed loss of personhood or self of an individual with dementia. However, we wish to alert readers about the non-shared idea of what self and personhood mean.

2 This is the definition given by the Centers for Diseases Control and Prevention, the leading national public health institute of the USA (see <https://www.cdc.gov/longtermcare/index.html>).

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