

PALLIATIVE CARE IN DEMENTIA

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SUMMARY

The Dementias are common neurodegenerative diseases which gradually deteriorate and eventually become fatal. However, hospice care is usually made available to patients suffering from Cancer, while patients who suffer from other chronic conditions such as dementia are not usually offered such care. However the lessons which have been learnt regarding hospice palliative care could be applied with some modification to the care of patients with Dementia. This article attempts to discuss the present literature about palliative care in Dementia, in order to clarify the evidence which underlies the European Association for Palliative Care 'White paper defining optimal palliative care in older people with dementia'.

Key words: dementia - palliative care - hospice care - chronic illness - neurodegenerative diseases

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INTRODUCTION

The Dementias are common neurodegenerative conditions in which there are impairments of Memory, Cognition and Behaviour which, as the illness progresses, eventually cause dependence and disability. Eventually the patient becomes so debilitated that the illness becomes fatal.

All over the world, 35.6 million people live with dementia, and its prevalence is expected to double in Europe between 2010 and 2015 and is expected to more than triple in Asia and Africa (World Health Organization 2012, Alzheimer's Disease International 2010).

ISSUES RAISED

The gradual deterioration of patients with dementia over several years has important repercussions for the patients' relatives and healthcare providers who struggle to provide appropriate care (World Health Organization 2012).

There are multiple barriers to end-of-life care delivery for patients with dementia. Dementia is often not being viewed as a terminal illness. There are communication difficulties with both the patients and their relatives regarding care preferences, inappropriate assessment and management of symptoms (Sampson 2005, Sachs 2004).

Husebø (2005) has argued against painful and unnecessary treatments violating basic human rights for weak elderly people suffering from dementia, which he has pointed out are widespread in Europe (Husebø 2005). The answer is the development of palliative care in the treatment of patients with dementia.

In 2005, a report on palliative care, by the health committee of the House of Commons recorded that there were great inequities in the availability of palliative care for patients with cancer as compared to patients with dementia (Hughes 2005).

It was stated that In the United Kingdom, people die in hospices almost solely from cancer, although it accounts for only 25% of all deaths. However patients dying from dementia are known to have healthcare needs which are comparable with those of cancer patients (Hughes 2005).

METHODS

During a separate project, while doing a literature search regarding Shared care between Primary and Secondary Care in the treatment of Dementia, we carried out a subsidiary search in Pubmed for papers discussing Palliative Terminal care in Dementia within the group of papers which were generated when we applied the key words 'Shared Care in Dementia'.

It became evident from the search that, whereas the principles of Palliative Care could to be applied to patients with dementia, they needed to be adapted to deal with the specific circumstances of Dementia Patients.

This would appear to have been achieved by 2014 by the 'White paper defining optimal palliative care in older people with dementia' which was produced as a result of a Delphi study carried out by The European Association for Palliative Care (van der Steen 2014, Nakanishi 2015).

WHAT IS THE EAPC FRAMEWORK?

The European Association for Palliative Care has developed a framework i.e: consisting of eleven domains each providing recommendations for optimal care. It includes 11 domains & 57 recommendations (van der Steen 2014). The domains and recommendations were developed as part of a Delphi study with 64 experts, 23 countries, with 9 experts being from Middle and Far East (van der Steen 2014). Here we describe the various domains of the EAPC framework and attempt to describe further recent work which has contributed to the further development of these domains.

Domain 1 - Applicability of palliative care

It is important to recognise that dementia is a terminal condition. Therefore the most important aim in the terminal phase of the disease is to improve quality of life, while maintaining function and maximizing comfort (van der Steen 2014). Hence specialist palliative care is needed (van der Steen 2014). There needs to be a baseline palliative approach which is inclusive, constituting a care pathway which starts off at the point of diagnosis and includes referral for treatment of symptoms and other health care problems (van der Steen 2014).

Roberts (2014) points out that persons with dementia who move into a care home deserve palliative care. He describes a workshop intended to incorporate a palliative approach into dementia care for care home residents (Roberts 2014). Participation in the workshop increased knowledge, skill and confidence to incorporate a palliative approach into care for people with advanced dementia and their families (Roberts 2014).

Samsi et al. (2014) has commented on the difficulty of developing care Pathways for Dementia. Samsi points out that uncertainty tends to be typical of the experience of living with dementia (Samsi 2014). Because of the uncertain illness trajectory and the unpredictability of levels of deterioration and stability in symptoms, persons who are given a diagnosis of dementia often live with uncertainty and anxiety and will often find it hard to make plans or decisions about the future (Samsi 2014).

Samsi (Samsi 2014) comments that persons with memory problems and caregivers may find themselves navigating a maze of services, practitioners, assessments, and memory tests, with limited understanding of the meaning of test scores and with little information about what support is available (Samsi 2014).

Samsi agrees that, given the uncertainty, the apparent clarity and certainty of a "dementia care pathway" may be attractive (Samsi 2014). However he points out that, the term "dementia care pathway" has multiple and overlapping meanings, which can cause further confusion (Samsi 2014).

Therefore Samsi distinguishes four meanings of "dementia care pathway" (Samsi 2014):

- a method for the management and containment of uncertainty and confusion, which is useful for the professional and also for the person with dementia (Samsi 2014);
- a manual for sequencing care activities (Samsi 2014);
- a guide to consumers, which will indicate which patients are eligible for particular care activities, or a guide to self-management for dementia, indicating the appropriateness of specific care activities in particular conditions (Samsi 2014);
- a manual for "walking with" the person through the development of the illness (Samsi 2014).

Different care pathways have been developed in the UK, and there are particular emphases on key points in the pathway (Samsi 2014), including:

- early symptom identification and first service encounters,
- assessment process,
- diagnostic disclosure,
- postdiagnostic support,
- appropriate interventions (Samsi 2014).

Clearly, terminal palliative care will be a final important appropriate intervention within such a care pathway, provided there is shared understanding of the pathway and its use among all professionals, patients and family members who are using the pathway (Samsi 2014).

Domain 2 -Person centered care

The emphasis in this domain is on communication and shared decision making (van der Steen 2014). The patient and the family needs and preferences are central to palliative care. Therefore providing of information and a shared decision making process should reflect this (van der Steen 2014).

Miller et al. (2014) have shown that while not all persons with dementia are excluded from participating in the decision-making process, there is a broad spectrum of what constitutes shared decision-making in dementia (Miller 2014). They recommend that there is need to better promote shared decision-making among persons with dementia and their family carers (Miller 2014).

Advance care planning consists of preparing care choices for when persons no longer have decision-making capacity (Ampe 2015). It is of utmost importance for patients with dementia, but is often not realized for patients with dementia, particularly those living in care homes (Ampe 2015). Advance care planning includes discussing care choices and making decisions and is similar to shared decision-making, which is the involvement of persons and their families in care and treatment decisions (Ampe 2015), with the difference that the discussions are about what may happen in the future, when the patient is not in a position to make decisions.

Advance care planning facilitates communication and understanding of preferences, however the use of advance care planning in primary care appears to be low (Brazil 2015). It appears that both the uncertain course of dementia and the difficulty in communicating with patients who are living with dementia are problems which are significantly challenging for GPs who may attempt to initiate discussions about the aims of care (Brazil 2015).

Brazil et al. (2015) surveyed 133 GPs about their views on advance care planning (ACP). While most of the GPs regarded dementia as a terminal disease (96.2%) only 37.6% agreed that palliative care can be commenced at the time of diagnosis and not just when dementia had become severe (Brazil 2015). Most of the

GPs believed that early discussions would make easier decision-making during advanced dementia (61%) (Brazil 2015), however the GPs were divided about whether advance care planning should be started at the time of diagnoses (Brazil 2015). While most GPs felt that GPs should take the initiative to introduce and encourage advance care planning (Brazil 2015), most of them accepted the need for increased knowledge, so that they could involve families in caring for patients with dementia at the end of life (Brazil 2015). Furthermore the GPs requested a standard method for documenting advance care planning discussions (Brazil 2015).

Brazil et al. concluded that the choice of the best timing of advance care planning discussions should be determined by the readiness of the patient and the family carers to face the end of life (Brazil 2015). Advance care planning discussions will be helped by educational interventions aimed at helping the patient and the family carers achieve shared decision-making with their GP when considering options for future care (Brazil 2015). Pazart et al. (2011) used a card sorting method to identify the points which were made during decision-making discussions with patients and carers, and found this helpful.

It is clear that Advance care planning will lead to Advance patient directives. 'Advance patient directives are anticipatory medical directives made by competent individuals to be used when there is eventual future incompetence' (Vollmann 2001). Thus they are used appropriately for patients who are competent in the early stage of dementia to document their will as decided by themselves to be implemented when they will be in the advanced stages of dementia (Vollmann 2001). It is therefore important that patients, family members, and physicians make use of advance directives as part of treatment and care planning, in order to document earlier shared decision-making by patient, family members and physician in order to bring about appropriate treatment planning for patients with dementia (Vollmann 2001). This is why the concerns raised by Brazil that advance care planning is not always carried out by GPs (Brazil 2015) need to be addressed.

Domain 3 - Setting care goals and advanced planning

It is important that the discussions in which advance care planning is carried out lead to the setting of care goals to guide treatment that meets the patient's and family's preferences. This is why the process ideally starts soon after the diagnosis, at the stage when the patient may still be involved, and it needs revisiting over time as the needs change.

Forbes (2000) points out that this may be difficult because family members made decisions in an emotional climate of overwhelming burden and guilt (Forbes 2000). It is suggested that this is because they feel that their loved one's life had been robbed of personhood, and often they do not recognise the changes associated with decline due to a dementia-related illness as part of the trajectory of dying (Forbes 2000). Thus, as

the disease proceeds on its trajectory towards death, there can be expected to be changes in the patient's and the carers' needs which must inevitably lead to changes in the goals of care (Forbes 2000).

Domain 4 - Continuity of Care

This should be advocated by all disciplines and when patients are transferred from one team to another. This is facilitated by appointment of a central coordinator.

Many issues will arise which will certainly be best solved with continuity of care. One issue to arise is that there will be difficulties with relating to patients who have lost their common shared world with their carers (Hertogh 2004). This can lead to particular problems with communicating with the demented patient who is no longer able to understand the reality of the diagnosis of dementia (Hertogh 2004). Hertogh (2004) has described this problem which arises in discussion between nurses and patients concerning truth telling and acting truthfully in relation to demented patients (Hertogh 2004). Special training for nurses is needed to help deal with this situation.

Housing for demented persons may become a problem, and this will lead sometimes to the need for specifically designed accommodation.

Reitinger (2010) describes community based housing for people with dementia (Reitinger 2010). It appears that "shared flats for people with dementia" are good places for death and dying (Reitinger 2010). In such units, close relationships, good communication with relatives and highly motivated professionals can be regarded as powerful resources (Reitinger 2010).

In the above examples it seems clear that having a central coordinator to provide continuity of care is very important.

Domain 5 - Prognostication

Discussing the terminal nature of the disease may help prepare for the future. Prediction of death is difficult but the best predictions combine clinical judgement & prognostic tools.

It is of interest that, despite the importance of good prognostication of the illness course, Nakanishi et al. have pointed out that this is not referred to in National Dementia Strategies (Nakanishi 2015).

Domain 6 - Avoiding inappropriate treatment

Avoiding aggressive, burdensome, and futile treatment is extremely important. Thus hospital transfers, any kind of treatment should be considered in relation to the agreed goals of care (van der Steen 2014). In Particular, restraint and permanent enteral tube feeding should be avoided as a rule. It is clear that the patient's comfort and quality of life should be the most important considerations in this situation.

Much literature discusses the issue of permanent enteral tube feeding (Schwartz 2014, American Geriatrics Society 2014, Lopez 2010). The American Geriatrics Society have a position statement on feeding tubes

in advanced dementia (American Geriatrics Society 2014). They argue that when eating difficulties arise, feeding tubes are not recommended for older adults with advanced dementia (American Geriatrics Society 2014). Instead careful hand feeding should be offered because hand feeding has been shown to be as good as tube feeding in dealing optimally with such outcomes as death, aspiration pneumonia, functional status, and comfort (American Geriatrics Society 2014). They argue furthermore that tube feeding is associated with agitation, greater use of physical and chemical restraints, use of healthcare resources due to tube-related complications, and development of new pressure ulcers (American Geriatrics Society 2014). Maybe it could be added that hand feeding is a much more personalised intervention between carer and patient.

Schwartz (2014) accepts that, gastrostomy tube placement or other long-term enteral access devices should be withheld in patients with advanced dementia conditions (Schwartz 2014). However Schwartz also emphasizes that the autonomy of the patient or surrogate decision maker should be respected, as should the patient's cultural, religious, social, and emotional value system (Schwartz 2014). Schwartz advises that clinical practice needs to address risks, burdens, benefits, and expected short-term and long-term outcomes, and these should be considered when considering changes in practices regarding feeding of individual patients (Schwartz 2014).

Lopez (2010) has shown that a physical environment which promotes the enjoyment of food, administrative support, and empowerment of staff to value hand feeding as well as shared decision-making processes involving family members leads to a lower rate of tube feeding in patients with dementia (Lopez 2010).

Domain 7 - Optimal treatment of symptoms

Many symptoms maybe interrelated and treatment is helped by a holistic approach. In treating symptoms it is important to integrate the views of more care givers. Both pharmacological and non pharmacological treatments should be used.

Givens et al. (2009) showed that out of a group of 232 symptoms on which decisions had to be made for of nursing home residents with advanced dementia ,the following were the most common; feeding problems (27.2%), infections (20.7%), pain (12.9%), dyspnea (8.2%), behavior problems (6.9%), hospitalizations (3.9%), cancer (3.0%), and other complications (17.2%) (Givens 2009). Support of those who have to make the decisions about these conditions is clearly very important (Givens 2009).

Di Giulio et al. (2009) described the treatment of patients with dementia in their last month of life in seven large Italian units. Within this final month, 'patients were prescribed antibiotics (71.6%), anxiolytics (37.1%), and antidepressants (7.8%) (Di Giulio 2009). Twenty-nine patients (20.5%) were tube- or percutaneous endoscopic gastrostomy (PEG)-fed (Di

Giulio 2009). Most patients (66.6%) were also hydrated parenterally (72 intravenously, 15 by hypodermoclysis) (Di Giulio 2009). Di Giulio reported that some form of physical restraint was used on many patients – up to 58.2%. This included bed-rails and other immobilizers (Di Giulio 2009). It was also noted that almost half of the patients had pressure sores (Di Giulio 2009).

In particular, in Di Giulio's paper, it was reported that during the last 48 hours of life, a number of interventions were reported which could be considered inappropriate (Di Giulio 2009). These included tube feeding (20.5%), intravenous hydration (66.6%), antibiotics (71.6%), and life-sustaining drugs (34.0%) (Di Giulio 2009).

Di Giulio argued that some of these findings may suggest that care was in some ways suboptimal, and also that the patients were not seen as terminal (Di Giulio 2009).

Domain 8 - Psychosocial & spiritual support

Psychosocial & spiritual support may vary throughout the disease process. Spiritual care should not be neglected. Religious activities should be recognized and acknowledged to be helpful.

A number of papers have been written about spiritual care during the latter stages of Dementia.

Mooney (2004) has pointed out that there is a lack of any theoretical framework which will help to understand what may be happening to a markedly confused person spiritually, and how a person with progressive cognitive impairment could be able to maintain a relationship with God who may only be remembered vaguely, if et al. (Mooney 2004).

Mooney (Mooney 2004) points out that elderly persons with dementia who come from the Judeo-Christian tradition do often respond to various rituals of their faith, and do so verbally, physically, and emotionally (Mooney 2004). Therefore, the use of familiar prayers, Bible readings, hymns, and attendance at worship services where collective memory is shared can serve as memory prompts to enable the reconnection of the person, both to the faith community, and to the person's understanding of God (Mooney 2004).

Thus, a spiritual care ministry to older people with dementia is actually a ministry of memory (Mooney 2004).

Daly (2014) has pointed out that although spirituality is a complex and subjective concept, it is a fact that spiritual wellbeing is an important component of a person's overall well-being and therefore that the spiritual support of patients is central to nursing care (Daly 2014). If persons with dementia may become distressed if they are not be well-supported in this aspect of care (Daly 2014). It is possible to identify the person's spiritual needs by taking the person's history (Daly 2014) or, in patients with advanced dementia, by asking the person's relatives or other 'significant others' about the important spiritual aspects of the person's life (Daly 2014). Daly advises reflective practice and

meaningful engagement with the person with dementia, so as to facilitate shared understanding in order to help care for these patients (Daly 2014). The provision of individualised patient centered care of a patient with dementia must include the support of the spiritual and religious beliefs of the person (Daly 2014). Such support must be part of a multi-disciplinary collaborative method of delivering care (Daly 2014).

Domain 9 - Family care and involvement

As the disease progresses, families need education about their changing roles and in order to enable them to give adequate support. This is especially so when they are about to suffer loss. Based on our previous discussion, high-quality palliative care for people with dementia should be patient-centered, family-focused, and include well-informed and shared decision-making (Penders 2015).

Unfortunately the present literature suggests that families may not get sufficient help in this regard.

Penders et al. (2015) showed that, in a study in Belgium, family carers were often unaware that their relative had dementia (Penders 2015), and this was so in one-fourth of cases of dementia and one-fifth of advanced dementia. This posed important problems for the provision of optimal care and end-of-life decision-making (Penders 2015). This was especially so if the patient was an inpatient in a nursing home, therefore it is important to improve communication strategies for these families (Penders 2015).

Domain 10 - Education of health care teams

It is clear that the whole caring team needs training and adequate skills for applying a palliative care approach. The previous domains have indicated a number of competences which should be included in training dementia care teams (Perrar 2014).

Domain 11- Societal and ethical issues

There is general support in the literature for the view that patients with dementia should have access to palliative care. Equally families need support in the caring for the patient, while professional care givers should be educated and motivated. Furthermore, public awareness should be increased. The public need to be made aware of what national strategies for dealing with the problem of dementia are and how they can contribute to these strategies. Hence there is much that needs to be done, in terms of education for both professionals and families, as well as commissioners of services and society at large in order to achieve the availability to all of palliative care in Dementia.

CONCLUSION

It is clear from the present literature that it is important to understand the concept of palliative care in dementia. Furthermore, in order to deliver such care, it is important to educate caregivers, families and the

nation regarding the importance of palliative care in dementia, and that palliative care for dementia should be offered within an appropriate framework.

This being the case, one must be concerned by the finding by Nakanishi (Nakanishi 2015) that, while many of the domains listed in the European Association for Palliative Care (EAPC) whitepaper are listed in the health strategies of various countries, palliative care in dementia is not listed specifically in these strategies.

Furthermore, it is evident that there is a very great role for primary care in the development of palliative care for patients with dementia. Present hospice provision is fully taken up with the care of other forms of chronic illness, so new provision of hospice places will be needed, however, many patients who suffer from Dementia are presently treated in Nursing Homes, which receive their medical input from General Practitioners and their teams. Equally, inevitably, many patients who suffer from Dementia will also need to be treated at home, so 'Hospice at Home' type services will need to be expanded, and these too will require input from GPs and primary care teams. Central to this expansion of services, Nurses who specialise in Palliative care for Dementia Patients, in the UK known as 'Admiral Nurses' will play a leadership role in collaboration with Primary Care Teams and GPs in the development of services for these patients.

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Conflict of interest:

I Mark Agius is a Member of an advisory board to Otsuka, Japan.

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