



The Nursing Management Required Ensuring Patients with End Stage Dementia Receive Effective End of Life Care in a Nursing Care Home Setting

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Abstract

This case study is an example from practice whilst working in a nursing home setting, and it will describe how a holistic approach to care provided to a resident, suffering from dementia at end of life, ensured a peaceful death. The importance of advance care planning and effective pain and symptom management in end of life care will be explored. The psychosocial issues experienced by the resident and their family and any ethical issues associated with the delivery of care will be addressed. The factors and challenges that need to be overcome, in order to ensure effective pain and symptom management for the dying patient, particularly in a nursing home setting are discussed. Finally, this article will make recommendations for future practice.

Keywords: Dementia; End of life care; Advance Care Planning; Pain management; Multidisciplinary working; Nursing home

Introduction

End of life care is as important, if not more so, than any other type of patient care, and it involves treating all individuals nearing the end of life with compassion, dignity, respect, and ensuring their last few days are comfortable and pain free [1,2]. The purpose of Advance Care Planning is to ensure people live according to their preferences and values until the end of their life [3,4]. Ampe, et al. [5] and Sampson, et al. [6] propose that a more efficient use of advance care planning will result in better quality and more person-centered care. Approaching the subject of Advance Care Planning requires skillful use of communication, whilst maintaining sensitivity, expressing sympathy and applying active listening. Additionally, approaching the subject of end of life care gently, with a soft voice, leaving a few pauses to give families the opportunity to express their thoughts and feelings, and to empathise with any emotional reactions they may have [7-9]. Caring for a patient with dementia dying in a nursing home setting requires knowledge, expert nursing skills and effective multidisciplinary working (National Institute for

Health and Care Excellence) [10]. The relationship between healthcare professionals, residents and families is based on respect, transparency, equality, mutuality and collaboration in the decision-making process [11].

The Case Study

In a nursing home setting, the team had been caring for a 92 years old resident called David (pseudonym). David was diagnosed with dementia at the age of 85 and was becoming increasingly frail and withdrawn. Dementia is characterised as a progressive disease that affects the brain [12-14]. A sudden deterioration in David's condition was evident. His oral intake diminished, and he stopped engaging with people around him. The General Practitioner (GP) reviewed David, in discussion with the nursing team, confirmed that he had entered the final stages of life. End of life care management was agreed by the team, meaning he would be kept as comfortable and well as possible, additionally his symptoms would be efficiently managed in order for him to die with dignity.

Due to his advanced dementia and inability to make his own decisions, David was unable to reason or express his wishes, therefore lacked capacity to contribute towards his care. Everyone is considered as having capacity to make decisions for themselves unless it is proven otherwise [15,16]. Preparation was made for a sensitive conversation with David's family, including his daughter and son about what they thought their father's wishes would be. His son wished for his father to remain comfortable in the nursing home, as he believed it was his preferred place of care. However, his daughter's preference was for her father to be taken to hospital, should he develop any conditions, that may have reversible causes. This highlights the different viewpoints people may have regarding ethical and sensitive issues in end of life care.

Family Involvement and Support

Stonehouse [17], Brooks and Vigate [18] and Anderson, et al. [19] explain the importance of nurses being able to approach family members whilst remaining unbiased and maintaining a professional manner. The relationship between healthcare professionals, residents and families is based on respect, transparency, equality, mutuality and collaboration in the decision-making process [11]. Nurses must adhere to ethics by being honest and transparent with residents families, respecting their opinions during delicate conversations, with the aim of building a good relationship with them [10]. This consequently enables them to talk about end of life care on their own terms [20].

As David's son had Lasting Power of Attorney in Health, he was legally appointed to act in his father's best interest with regards to his treatment and welfare. Nonetheless, he wished to include his sister in discussion about the best treatment plan for their father; this allowed his sister to participate in the shared decision-making process. Anderson, *et al.* [19] and Jones, et al. [21] highlight the importance of families being united in end of life care decisions, with the purpose of accomplishing outcomes of care with the aim of ensuring their loved ones are provided with the best care possible. The nurses on the unit worked collaboratively with David's family by discussing his wishes and preferences throughout. An Advance Care Plan was drawn up and it was decided with agreement from David's family and the multidisciplinary team that it was in his best interest to stay in the nursing home for end of life care.

When residents are not provided with the one-to-one care they are entitled to, it can result in them dying on their own without being offered some form of comfort [22]. For that reason, nurses aim to encourage families to participate actively in their relatives' care, for instance spending time with them, talking to them, offering mouth

care and providing company that is of a great value for the one nearing the end [23,24]. Conversely, it is important to take into consideration, that families vary, and therefore not everyone is comfortable with such a proposal, as they may find physical changes of their relative's deterioration distressing and upsetting [25,26]. Relationships between healthcare professionals and families are of a great value, consequently effective and transparent communication, offering families support and keeping them informed, are of vast importance during their psychological distress and their own experience of bereavement [27]. Nevertheless, it is imperative that these psychosocial aspects, that have effects on families and residents, are skillfully managed [28]. It is essential that both support and understanding are offered to families and loved ones at such a difficult time [2,29]. This highlights the importance of offering family involvement, known as shared-decision making [30,31]. Nevertheless, healthcare professionals must take into consideration that family involvement, is a very individual process for everyone, and they must respect people's choices in this matter [32].

Holistic Care

End of life care is a complex and sensitive area of practice as viewed by the Alzheimer's Society, [33]; Power [34] and Warnock, [28]. Hayes, et al. [35] and Macaulay [36] agree that end of life care is an important aspect of one's life. It involves making residents as physically and psychologically comfortable and pain free as possible, to keep them calm, without any agitation or worry. McElligott, et al. [37] and Burnard and Gill [38] highlight that end of life care clearly links to a holistic approach to care. Therefore, it is vital to treat every resident holistically at all times by including all aspects of care, for instance spiritual, physical, psychological and social. It takes into consideration residents' emotions, thoughts, culture, attitudes and opinions, which are contributing factors in recovery, contentment and fulfilment [39,40]. Its purpose is to respect human dignity [41]. For some residents, it is important to have some form of religious guidance during the last days of their life, that is known as spiritual care, which is an aspect of the holistic approach to care [35,42]. It follows that, a holistic approach to care encompasses looking after residents with the view of managing their physical and psychological wellbeing.

Symptom Control – Pain Management

Nurses have a duty of care to make residents comfortable and pain free [20]. David was unable to express verbally any pain he experienced due to his advanced dementia. Gregory [43] and Regan, et al. [44] highlight the challenges of assessing pain in patients with cognitive impairment, and therefore recommends monitoring signs of non-verbal communication. It was recognised from David's non-verbal communicators that he displayed signs of pain during the

time when he was re-positioned in bed, such as grimacing. In order to assess pain adequately, there are pain assessment tools available, for example the Behaviour Pain Assessment Tool [45]. This tool assesses pain in patients, who are unable to communicate, however are able to express themselves through non-verbal communication skills. Nevertheless, these tools are only beneficial if they are used efficiently. For pain to be effectively and skillfully managed, nurses must be equipped with proficient communication skills and knowledge [25,30,46]. Additionally, nurses should not concentrate on pain as a factor, but view the resident as a whole [47]. Being in pain causes distress and discomfort; consequently, it is paramount to treat any symptoms that patients may experience in order to make them feel comfortable, as the focus is on quality of life, not quantity [1,38].

Multidisciplinary Working

The healthcare professionals caring for David, ensured that he had someone by his side, whether his family, or nursing staff. In such scenarios, teamwork is of crucial importance [10]. Blais and Hayes [48], Linstead, et al. [49] and Popanicolas, et al. [50] highlight that many organisational issues can influence patient care, for example a shortage of staff. Therefore, the importance of effective team working, honest communication and respecting each professional's skill base and involvement is key, particularly in a nursing home care setting. Goodman and Clemow [51] agree that it is vital for the multidisciplinary team to work in partnership with the intention of achieving the goal of supporting residents' wishes.

Education in End of Life Care

Continued efforts to provide nurses with the necessary skills, education, competence and confidence, may empower them to provide valuable support for residents and family in order to achieve their goals at end of life [52,53]. Investing in nursing education and professional development is important in order to ensure residents are being provided with high quality care by nurses having an up to date knowledge and support when required [54]. The opportunity to undertake comprehensive end of life care training could enable nurses and other healthcare professionals to gain insight and understanding of the challenges and knowledge around end of life care. Additionally, allowing staff to feel more confident, and to improve the best possible care for those nearing the end, as it is equally as important, if not more [55].

Conclusion

There are challenges that still require addressing when providing effective care for people suffering from dementia, particularly as they reach end of life. For instance, the

inability to express pain or discomfort, therefore the use of pain assessment tools by nurses is beneficial. Research clearly confirms that if Advance Care Planning and effective communication are in place, people are more likely to have a peaceful and dignified death. It is essential in end of life care, for communication to be transparent, honest and person-centred. This case study supports this, by highlighting the importance of skilled and adequate symptom management and effective multidisciplinary working at end of life when caring for vulnerable patients in nursing home settings. David died peacefully, with his family and the nursing team by his side whilst being treated with the utmost respect and dignity.

It is important to note, that the manner in which healthcare professionals provide care for a dying resident, can reflect on the care previously delivered, whether in an acute or chronic setting. Consequently, this can have a major impact on the final memories for relatives who have witnessed the care given.

Key Points

- Advance care planning is key to ensuring preferred place of care and achieving patient's wishes.
- Effective honest communication with patients and family is paramount.
- Multidisciplinary working and recognition of professional skills is required in all aspects of end of life care.
- Skilled pain and symptom management ensures a peaceful and dignified experience.

CPD Reflective Questions

What are the challenges of looking after a dying patient with dementia in a nursing home setting?
 Why is Advance Care Planning important in end of life care?
 How can healthcare professionals working together ensure the provision of effective care?
 What skills are required for efficient symptom management at the end of life care?

Conflict of Interest

None

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