Mini Review
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Optimal symptom control in last days of terminally ill patients

Abstract

Death is a biological imperative and inevitable. Adequate control of symptoms of a terminally ill patient is a challenging task for most end-of-life care professionals. The sole aim to provide comfort till the end of life with a holistic approach is necessary. In keeping with Liverpool Care Pathway as a guide, care of the terminally ill in their last days should be individualized from a more humanistic perspective. It should not be a 'Tick Box Exercise' and never a 'One Size Fits All' type. Once a 'diagnosis of dying' is made, spending on unnecessary medical interventions should be curtailed and natural death process should be allowed to continue. If available, it is always desirable to seek the opinion of specialist palliative care service team in the management of terminally ill patients. Shared decision making and open communications with all concerned are of paramount importance in end-of-life care. This mini review attempts to identify common physical symptoms and an appropriate intervention.

Keywords: death and dying, end of life care, last days of dying person, symptom control, liverpool care pathway

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Abbreviations: LCP, liverpool care pathway; NSAID, non-steroidal anti-inflammatory drugs; SNRI, serotonin-norepinephrine reuptake inhibitor

Introduction

Yes, we all know. Everyone dies. The end of life is going to be a simple decline into nothing. A person identifies as if there is no tomorrow, how he/she feels like? Everything that is humane-waking, feeling, dreaming, eating, smiling, laughing, loving, hoping- all comes to an end. How to make a death enjoyable? This is a question humanity has been exploring since time immemorial. Patients experience more physical symptoms towards the final days of life. Patients worry about the financial stability and wellbeing of their loved ones, they worry about whether their wishes will be honored, they worry about the protection of their legacy. These last few days are very difficult and should be viewed with a degree of apprehension.[1] Escalation of symptoms or diminished mental status make the final days very difficult.[2] End of life symptoms are unique to each and every individual. All attempts to ensure the patient comfort should be made. This is a very challenging time for the individual as well as the carer.

Review of literature

A 1990 study carried out in a single institution on New Zealand, the authors identified 9 symptoms in the last 48 hours of life.3 They are listed in Table 1.

The care of terminally ill should follow sole aim of promotion of comfort. Optimal symptom management is the most important aspect. Physical and spiritual needs also should be addressed. A patient's transition from chronic illness to final days of life is hard to recognize. Situations like non-malignancy and end organ failure are even more difficult. As per Boyd and Murray, if the answer to the following 4 questions is "YES", care of dying can be initiated.[4]

Table 1 List of symptoms

Rank	Symptoms	Frequency %
1	Noisy and moist breathing	56
2	Pain	51
3	Restlessness and agitation, jerking, twitching, plucking	42
4	Incontinence of urine	32
5	Dyspnea	22
6	Retention of urine	21
7	Nausea and vomiting	14
8	Sweating	14
9	Confusion	9

1. this patient be in last days of life? (Confining to bed, difficulty in taking medications /feed, drowsy)
2. Was this deterioration expected in the given condition?
3. Is further life prolonging treatment is inappropriate?
4. Have the potentially reversible causes of deterioration been excluded?

If the diagnosis of dying is in doubt, give treatment and review within 24 hours. Optimal symptom control is essential for a peaceful death. Patients do die peacefully.[5] To now when the death is coming, to understand what can be expected when one reaches the end of life, to have access to spiritual and emotional support, to have a sense of autonomy on one's wishes and preferences, and above all a proper management of distressing symptoms are some of the essential needs of a dying patient.[6] The Liverpool Care Pathway (LCP) developed by the Marie Curie Hospice and the Royal Liverpool University was an attempt to harmonize the care of dying patients irrespective of the place of care.[7] The initial enthusiasm created by the LCP for the care of dying patients was short-lived. There was a widespread public outcry to withdraw it on account of alleged deliberate denial of food and hydration to dying patients, use of incentive payment given for the implementation of LCP. Premature diagnosis of imminent death

can cause carer dissatisfaction.[8]Many families thought that their relatives could and should have lived longer if the pathway was not incorporated into the care. Lack of training in the use of LCP, use of LCP inappropriately without sufficient discussion with the patient and family, lack of compassion from the health care workers as they tend to use LCP as a 'Tick Box' exercise, use of sedatives and analgesics even while they were not indicated, were also some of the reasons of media criticism. This led to the appointment of an independent review commission led by Julia Neuberger and the panel declared LCP as a wrong approach to deal with death and dying patients, highlighting the ethical, safety, negligence and the lacunae in diagnosing death and dying.[9] The LCP was abolished after a period of around 25 years of its initial conception and inception. Following the footsteps of LCP, many care pathways have been developed and some are still in use.[10] A 2016 Cochrane review, the evidence concerning the clinical, physical, psychological or emotional effectiveness of end-of-life care pathways was found to be very limited.[11–13] However, the Care pathways can provide useful guidelines to avoid unnecessary biomedicalization of a patient on the account of unrealistic hope imparted. UK's leading training provider, the Gold Standard Framework, with a motto of "end of life care is everyone's business" is a practical systematic, evidence-based end of life care service improvement programme. A one-way track to death is not always possible. Care of the dying is complex, hence should be individualized. Proper management of physical symptoms is the key for quality of life at the terminal phase. Table 2 depicts the most important and frequently occurring symptoms at the end-of-life situations, their possible causes and broad management strategies. This is a very difficult cohort to conduct research due to a variety of factors such as environmental restrictions in critical care units, conflicts of care pattern between the professionals, over protective attitude of carer, cultural biases, poorly managed symptom control etc.

Table 2 Major symptoms of dying patients and management strategies

No.	Symptom	Possible cause/ s	Management	Others
1	Moist respiration(Death rattle). Note: Interventions, both pharmacological and non-pharmacological- has no clearcut evidence base.	Excessive secretions.	Atropine. Hyoscine butyl bromide. Scopolamine. Glycopyrronium. (any)	Suctioning. Change of position. Re assurance.[14,15]
2	Pain Note: Guttural noise made by patient may be an effort to check whether someone is around. Use of Fentanyl in imminent death may be discouraged on account of difficulty in titration of dose.	Exacerbation of existing pain. New pain. Incidental pain. Decubitus sores. Retention. Constipation.	Acetaminophen. NSAIDs. Weak opiates. Opiates. Note: Route of administration may be decided based on condition.	Treat the 'treatable' causes. Special attention to neuropathic pain. Tricyclics. Antiepileptics. SNRI.[16,17]
3	Restlessness, agitation, delirium, agitated delirium (hyperactive delirium)	Undue sedation Biochemical disturbances Unrelieved pain Bladder/rectal distention Infections Dehydration Cerebral anoxia Breathing difficulty	Levomepromazine Diazepam Midazolam Haloperidol Lorazepam Note: Midazolam is miscible with Morphine	Mnemonic: 'Dr DRE' Disease remediation Drug removal Environmental modifications Use of night light Do not use restraints if possible Reassurance [18–20]
4	Incontinence of urine/ Retention of urine Note: Root cause is seldom treatable	Loaded rectum. Drug related causes.	Padding. Indwelling catheter. External catheter.	Suppository. Enema. Manual removal of stools.[3]
5	Dyspnea Note: Routine oxygen is not required unless the patient has symptomatic hypoxia.	Underlying pathology. Anxiety. Fear.	Cool draft of air with fan/air cooler. Anxiolytics. Titer up the Morphine dose to reduce respiratory rate.	Presence of caregiver throughout. Relieve the perception of breathlessness. Nebulized saline for thick secretions.[3,21]
6	Nausea, vomiting.	Multifactorial.	Anti emetics, preferably in alternate routes other than oral route. Haloperidol.	Check whether the symptom is new or an exacerbation of existing one.[22]
7	Sweating.	Drug induced. Hepatic causes. Hormone imbalance.	Steroids. NSAIDs. Anticholinergics. Olanzapine.	Check for fever. Remove excess clothing.[3,23]

A person who is in the last hours/ days of life does not feel hungry or thirsty. Hence artificial hydration and nutrition are not necessary. Artificial hydration has no impact on a patient's survival.[24] Rarely symptoms like sedation and myoclonus can be relieved with hydration but increased fluid retention can cause more discomfort to patient.[25] Mouth care is important. Disposable oral foam swabs, ice cubes, mouth sprays and washes may be made use of.

Some emergencies also may be encountered, the most common one is terminal hemorrhage. It is commonly associated with head and neck cancers, hematological malignancies, tumors invading or at close proximity to major blood vessels. A careful evaluation of patient's drug history, stoppage of anti- coagulant therapy, appropriate use of sedative hypnotics, anxiolytics and analgesics may be considered. Use of dark towels to lessen visual distress, immediate disposal of clinical waste, reassurance to family members are other measures to be undertaken.[26] Seizure is another emergency, due to its ambivalence, a differentiation between and epileptic seizure and non-epileptic seizure is difficult. Cautious use of anti-epileptic drugs including Benzodiazepines can control seizures in terminally ill. Alternative administration such as intranasal, subcutaneous, or rectal application may be explored.[27] It should be noted that the stress faced by clinicians engaged in end-of-life care can cause burn out and compassion fatigue among them.[28] This in turn can become a major deterrent in imparting best possible care for a dying patient.

Conclusion

Management of end-of-life symptoms demands extreme balancing and patient approach from clinician. "One- size- fits- all" approach is not practical. Allowing a patient to die in an undignified manner with uncontrolled symptoms points to failure in the health care system. Effective management strategies are available for optimum symptom control of dying patients in the last days/hours of their life. It is always preferable to seek support from a specialist palliative care team.

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Conflicts of interest

The author declared that there are no conflicts of interest

References

1. Barham D. The last 48 hours of life: a case study of symptom control for a patient taking a Buddhist approach to dying. *Int J Palliat Nurs.* 2003;9(6):245–251.
2. Turner K, Chye R, Aggarwal G, et al. Dignity in dying: a preliminary study of patients in the last three days of life. *J Palliat Care.* 1996;12(2):7–13.
3. Lichter I, Hunt E. The last 48 hours of life. *J Palliat Care*. 1990;6(4):7–15.
4. Boyd K, Murray SA. Recognising and managing key transitions in end of life care. *BMJ.* 2010;341.
5. Wilkes E. Dying now. *Lancet*. 1984;1(8383):950–952.
6. Steinhauser KE, Christakis NA, Clipp EC, et al. Preparing for the end of life: preferences of patients, families, physicians, and other care providers. *J Pain Symptom Manage.* 2001;22(3):727–737.
7. "Care for the dying patient" (PDF). Liverpool Care Pathway for the Dying Patient (LCP). Marie Curie Palliative Care Institute. Archived from the original on 11 February 2023.
8. Delvin K. Controversial 'death' pathway. *The Telegraph.* 2009.
9. Neuberger J. More care, less pathway: a review of the Liverpool Care Pathway, *Social welfare*. 2013.
10. Bookbinder M, Blank A, Arney E, et al. Improving end-of-life care: development and pilot-test of a clinical pathway. *J Pain Symptom Manage.* 2005;29(6):529–543.
11. Pooler J, McCrory F, Steadman Y, et al. Dying at home: a care pathway for the last days of life in a community setting. *Int J Palliat Nurs.* 2003;9(6):258–264.
12. Chan RJ, Webster J, Bowers A. End-of-life care pathways for improving outcomes in caring for the dying. *Cochrane Library.*2016.
13. What is the Gold Standards Framework?
14. Wildiers H, Dhaenekint C, Demeulenaere P, et al. Atropine, hyoscine butylbromide, or scopolamine are equally effective for the treatment of death rattle in terminal care. *J Pain Symptom manage.* 2009;38(1):124–133.
15. Wee B, Hillier R. Interventions for noisy breathing in patients near to death. *Cochrane Database Syst Rev.* 2008;(1):CD005177.
16. Anekar AA, Cascella M. WHO Analgesic Ladder. *National Library of Medicine.*
17. Cuomo A, Bimonte S, Forte CA, et al. Multimodal approaches and tailored therapies for pain management: the trolley analgesic model. *J Pain Res*. 2019;12:711–714.
18. Hanks G, Cherny NI, Christakis N, et al. *Oxford textbook of palliative medicine*. Oxford university press. 2011.
19. Brummel NE, Vasilevskis EE, Han JH, et al. Implementing delirium screening in the intensive care unit: secrets to success. *Crit Care Med.* 2013;41(9):2196–2208.
20. Pandharipande PP, Ely EW. Humanizing the treatment of hyperactive delirium in the last days of life. *JAMA*. 2017;318(11):1014–1015.
21. Kumar M. The last 48 hours. *Sage Journals*. 2020;14(1):27–31.
22. Wood GJ, Shega JW, Lynch B, et al. Management of Intractable Nausea and Vomiting in Patients at the End of Life: "I Was Feeling Nauseous All of the Time. Nothing Was Working". JAMA. 2007;298(10):1196–1207.
23. Zylicz Zbigniew. Flushing and Sweating in an Advanced Breast Cancer Patient Relieved By Olanzapine. *J Pain Symptom Manage*. 2003;25(6):494–495.
24. Gupta S, Sengupta A. The last 48 hours. *Sage Journals*. 2014;7(10):587–594.
25. Good P, Richard R, Syrmis W, et al. Medically assisted hydration for adult palliative care patients. Cochrane Database Syst Rev. 2014;2014(4).
26. Ubogagu E, Harris DG. Guideline for the management of terminal haemorrhage in palliative care patients with advanced cancer discharged home for end-of-life care. *BMJ Support Palliat Care.* 2012;2(4):294–300.
27. Grönheit W, Popkirov S, Wehner T, et al. Practical management of epileptic seizures and status epilepticus in adult palliative care patients. *Front Neurol*. 2018;9:595.
28. Kearney MK, Weininger RB, Vachon ML, et al. Self-care of physicians caring for patients at the end of life: "Being connected... a key to my survival". *JAMA*. 2009;301(11):1155–1164.