Why more guidance is needed on palliative and end-of-life bowel care guidance

End of life: a need for bowel care guidance

In this article...

- Communication with patients about bowel care at the end of life
- Why assessment and advance care planning is important
- Managing constipation and faecal incontinence

Author Gaye Kyle is independent lecturer and recognised teacher, University of Ulster.


Patients receiving end-of-life and palliative care often need help to manage their bowel care. Although several policies on palliative care have been introduced in recent years, there is a lack of guidance specifically on bowel management for patients approaching death. This article highlights the gaps in guidance, and discusses how nurses can alleviate patients’ distress and best preserve their dignity while managing their bowel care.

At the end of life, patients’ functional dependency often increases, leaving them needing help to manage personal issues such as bowel care. Patients with life-threatening diseases have identified loss of dignity as a major concern as they approach death (McPherson and Murray, 2007). This is related to diminished control of their bodily functions and loss of privacy, particularly during intimate care such as washing, toileting and bowel interventions (Chochinov et al, 2002).

Constipation is one of the most common problems experienced by palliative care patients. It can cause extreme suffering and discomfort to those who often have multiple healthcare needs. It can also influence patients’ daily lives to such an extent that they become totally preoccupied by their bowels (Friedrichsen and Erichsen, 2004). In an attempt to control it, patients may refuse their analgesia (Hurdon et al, 2000). Persistent or poorly managed constipation also causes secondary problems such as urinary retention, urinary incontinence or terminal restlessness.

Effective symptom management is a cornerstone of palliative care but constipation management continues to be a problematic area. Evidence has shown even specialist nurses may lack the necessary skills to give effective bowel care for patients with malignant disease (Warnock et al, 2008) and assess bowel function according to bowel frequency rather than stool type and difficulty of defecation (Goodman et al, 2005), or using a bothersome score.

In recent years, policy concerning end-of-life care has increased significantly. The Department of Health acknowledged the importance of improving and standardising end-of-life services by developing the end of life strategy (DH, 2008). The European Consensus Group on Constipation in Palliative Care makes recommendations for everyday assessment, diagnosis and management of constipation, which are summarised in a useful algorithm (Fig 1; Larkin et al, 2008). The Liverpool Care Pathway for the Dying Patient (LCP) – a part of the end-of-life care strategy – is a model of excellence for care of the dying (tinyurl.com/the-liverpool-care-pathway).

In spite of these excellent examples, however, little guidance exists on how to manage some of the more complex areas associated with both palliative and end-of-life bowel care such as metastatic spinal cord compression, anal fissures due to localised malignancy, constipation caused by hypocalcaemia and the end stage of neurological diseases.

End of Life Care (National Audit Office, 2008) cites lack of knowledge and training of health workers as a further hindrance to giving appropriate end-of-life care. Skills for Care and Skills for Health identified common core competencies for effective end-of-life care to support staff development, training and education (Box 1; DH, 2009); in discussing these core competencies it may be possible to highlight where clinical guidance is lacking and the need for palliative/end-of-life bowel care guidance.

Communication

Any discussions involving bowel care need to be carried out sensitively before the terminal phase is reached. Constipation can be distressing and deeply embarrassing for patients, and they are often reluctant to discuss it.

Nurses may also find the subject of bowel elimination difficult. Nurses’ communication methods and questions should be sensitive to patients’ individual needs, remembering they may prioritise other symptoms such as pain and breathlessness over their bowel problems.
Some patients may find it difficult to express their discomfort from constipation. Often they use the phrase, “I’m not feeling right” because the constipation may mimic and enhance the general debility associated with progressive disease (Annells and Koch, 2002). If patients are unable to communicate their difficulties, the opinions and observations of their families or carers need to be taken into account, particularly if they are involved in patients’ intimate care.

Assessment and care planning
Assessment of bowels should be part of an overall holistic, methodical palliative care assessment, but comprehensive, validated end-of-life continence assessment tools or guidelines are lacking (Lawrie, 2007). Using integrated continence care pathways, such as those used by specialist continence services, could improve the quality of bowel assessments. However, a bowel integrated care pathway is not always appropriate because the emphasis at the end of life is on providing management that promotes comfort, rather than on curative treatment.

Constipation assessment should include establishing how the pattern of bowel movements have changed from previous bowel habits. Nurses should conduct a general physical examination, looking for evidence of abdominal distension, tenderness and the presence of abnormal bowel sounds. A digital rectal examination may be required to assess rectal loading or faecal impaction, as well as the consistency of the faecal material.

A proactive approach to bowel care is needed to prevent constipation or faecal loading occurring at the end of life (Kyle, 2008; National Institute for Health and Clinical Excellence, 2007). If health professionals take preventive measures and identify risks, undignified bowel interventions can be minimised (Ellershaw, 2003). The recent development of risk assessment tools for constipation may improve practice (Kyle, 2008).

Symptom management
How patients’ constipation is managed will depend on the cause and symptom profile. This in itself can present the health professional with dilemmas: the main predisposing factors for constipation are all associated with lifestyle and include insufficient fibre and fluid intake, limited mobility, and polypharmacy, but managing symptoms through lifestyle advice has little relevance for patients at the end of life. In addition, those with malignant diseases may also have loss of appetite, increased opioid medication and cachexia to take into consideration.

Opioids are an effective treatment for moderate to severe pain and breathlessness in palliative care but they predispose patients to a high risk of developing opioid-induced constipation. As such, prescribed laxatives may become less reliable, necessitating larger doses. Laxative prescribing should be individualised according to bowel function assessment rather than to the opioids prescribed (Bennett and Cresswell, 2003). In the UK a combination of a contact stimulant and faecal softener is recommended for general use in the Palliative Care Formulary (Twycross et al, 2007). If a patient has urinary incontinence, any laxative containing danthron should be avoided because of the risk of skin irritation and contact dermatitis.

In general, laxatives seem to be less effective in patients with malignant disease, often necessitating large doses. If there is no improvement in symptoms of opioid-induced constipation is suspected, health professionals can consider using a peripheral opioid antagonist in the form of a subcutaneous injection in combination with the laxative regimen.

If patients become profoundly uncomfortable due to a full rectum and are unable to take oral laxatives, rectal intervention may be necessary. Glycerine suppositories act as a rectal stimulant by virtue of the mildly irritant action of glycerol (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2011). Glycerine suppositories must be moistened before insertion, then placed along the rectal wall. All bowel care suppositories need body heat to dissolve for activation; if suppositories are placed in the middle of faecal matter they are likely to remain intact and useless.

Abdominal massage – also referred to as bowel or colonic massage – is anecdotally acknowledged by health professionals to be an effective management option for constipation as it is seen as relaxing and can relieve trapped wind. It may be used as an adjuvant to normal bowel management at the end of life but its value as a standalone intervention remains unproven.

Faecal incontinence is particularly problematic at the end of life; the most common causes at this stage are inappropriate use of laxatives, constipation with faecal impaction and overflow, and infectious diarrhoea. If faeces during the terminal phase are very loose, it is advisable to use a faecal collection system (NICE, 2007). This is a temporary device comprising a soft, flexible catheter that is inserted digitally into the rectum and held in place through a low-pressure balloon (Johnstone, 2005). Although there is little evidence to support the use of faecal collection devices at the end of life, arguably they provide a dignified way of dealing with this difficult problem.

An anal plug that is inserted into the anus where it expands can also be used to prevent involuntary faecal leakage or smearing on bed clothes. This can be left in position for up to 12 hours. Not all patients are able to tolerate anal plugs because they...
Nursing Practice
Discussion

FIG 1. RECOMMENDATIONS FOR EVERYDAY ASSESSMENT, DIAGNOSIS AND MANAGEMENT OF CONSTIPATION

- Patient complains of constipation
- Full bowel assessment
- Examine causes and risks
- Correctable
- First line: oral laxative - soften plus stimulant
- Improvement of symptoms
- Second line: consider using peripheral specific opioid antagonist if opioid-induced constipation suspected or rectal intervention
- No improvement of symptoms
- Third line: consider using peripheral specific opioid antagonist if OIC suspected, digital removal of faeces


References
Ellershaw J (2003) Care of the dying patient: the last hours or days of life. British Medical Journal; 326: 30-34.

can stimulate the defecation reflex, resulting in discomfort.

Faecal incontinence as a result of relaxation of the anal sphincters can be a sign of imminent death and may be contained by the use of pads (World Health Organization, 2003). The skin should be cleaned of faecal matter and moisture barrier creams should be used to prevent incontinence-associated dermatitis.

Patients approaching the end stage of neurological diseases, such as Parkinson’s disease and multiple sclerosis, may have already experienced some faecal incontinence or constipation since their initial diagnosis. Where possible, patients’ usual management regimens should be maintained. These may include trans-anal irrigation, a simple and effective intervention, which provides symptomatic relief (NICE, 2007). This procedure provides a dignified approach to bowel care that is cost effective because it reduces district nursing time; unfortunately few nurses know of its existence so it is rarely considered.

There is a lack of specific guidelines on how to manage the complex neurogenic bowel of a patient with metastatic spinal cord compression (MSCC), yet those for neurogenic bowel caused by spinal cord injury do exist (Spinal Cord Injury Centres of UK and Ireland, 2009). Whether these could also be used to help patients with MSCC is debatable, reinforcing the urgent need for comprehensive bowel care guidance in palliative care.

Advance care planning
Advance care planning is a process of discussion between patients and their care providers that may or may not include family and friends. Its aim is to understand individuals’ preferences to support their end-of-life experience. Little is known about what constitutes advance care planning, who is best to initiate these discussions and whether it will enhance peoples’ ability to choose their end-of-life care (Horne et al, 2009).

Although bowel care forms just a small part of the overall advance care planning, constipation or faecal loading can pose significant practical problems for carers at home by, for example, creating extra laundry from soiled bed linen. Community healthcare workers need to be aware that faecal incontinence during the terminal phase, together with the emotional burden of watching a loved one approaching death, may overwhelm a carer who may already be exhausted. This is important given that some patients may engage in advance care planning without family or carers present.

Conclusion
Constipation is common in palliative care where it can cause patients significant discomfort and distress. Nurses are pivotal in providing end-of-life interventions such as bowel care because they are in regular contact with patients.

Nurses need to be mindful of the many approaches to managing the condition. It may only be through the development of clear palliative/end-of-life bowel care guidelines that members of the profession will develop the knowledge that is needed to be able to implement effective symptom management. NT

ACA are publishing guidance on end-of-life continence care later this year.