Palliative care principles and pharmacy roles

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Palliative care is an approach that improves the quality of life of people with terminal illness, and their families, through the prevention and relief of physical, psychosocial and spiritual problems. According to the World Health Organization, palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten nor to postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life and includes those investigations needed better to understand and manage distressing clinical complications

General palliative care is appropriate for patients and families with needs of low-to-moderate complexity (e.g., those with stable disease whose condition and symptoms are not changing) and this is usually delivered by primary care professionals, for example, GPs and district nurses.

Specialist palliative care services provide care to patients and families with needs that are of moderate-to-high complexity (e.g., those with unstable disease, multiple comorbidities, uncontrolled symptoms or psychological distress). These can be delivered in a hospice or a hospital or in patients' homes, depending on where they prefer to receive care.

Traditionally, specialist nurses and doctors have been the main professionals involved in palliative care. Yet multidisciplinary working is essential when caring for patients facing terminal illness. Pharmacists, allied healthcare professionals, family support and healthcare assistants are among the professions involved in the provision of effective palliative care (see also Box 1, p318). Pharmacist input is described on p321.

End-of-life care

The care provided during the final few days, weeks or months of life can be broadly referred to as end-of-life care. Establishing a patient's preferred setting for end-of-life care and where he or she wishes to die should take place as early as possible and recorded appropriately.

In the past, only patients with needs of low complexity were managed at home but nowadays, as services have developed, patients with more complex needs are able to be managed at home.

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SUMMARY

Palliative care is an approach to managing the physical, psychosocial and spiritual problems experienced by people who are dying. The care provided during the final few days, weeks or months of life is broadly referred to as end-of-life care.

Co-ordinating care in the community is a major challenge in providing appropriate end-of-life care; the gold standards framework can be used to optimise non-specialist care for patients nearing the end of life. The Liverpool care pathway for the dying patient can be used to support the increased level of care needed in the final days and hours of life. Specialist palliative care pharmacists can tailor treatment to suit individual needs, while respecting patients' personal views about medicines.
The strategy suggests that more detailed information on end-of-life care needs to be gathered, but acknowledges the challenges within the specialism in establishing when end of life begins. From a practical perspective, clinicians can find it difficult to obtain written confirmation that a patient is now to receive palliative care.

Co-ordinating care in the community is one of the biggest challenges in end-of-life care. Often the patient is known to a number of healthcare teams, which can include the GP surgery, district nurses, hospital team, hospice team, and, within each team, a range of different professionals.

The GP remains the primary clinician for patients being cared for at home. Effective communication and information transfer is important in ensuring that the best level of care is achieved in the community. Access to services will vary depending on where patients live, which can cause difficulties when co-ordinating care. A patient's diagnosis can also affect which services can be accessed, with non-cancer patients traditionally having poorer access to specialist palliative care services than cancer patients.

Gold standards framework
The gold standards framework (GSF) is a systematic, evidence-based approach to optimising the care delivered by generalist providers for patients nearing the end of life.

The GSF was originally developed in 2000 by a GP with a special interest in palliative care (supported by a multidisciplinary group of specialists and generalists) as an initiative to improve palliative care services offered in primary care. It has developed and expanded over the past decade to meet the challenges of end-of-life care in the context of national health priorities (eg, the NHS end-of-decade to meet the challenges of end-of-life care in the primary care). It has developed and expanded over the past decade to meet the challenges of end-of-life care in the context of national health priorities (eg, the NHS end-of-decade to meet the challenges of end-of-life care in the primary care). The GSF has seven key recommendations, known as the seven Cs, described below.

Communication Each primary care team should compile a register of patients identified as having end-of-life care needs. This “supportive care register” should be used to plan and monitor patient care at regular healthcare team meetings in GP surgeries or care homes.

Co-ordination A GSF co-ordinator should be appointed from within the primary care team. He or she is charged with overseeing implementation and ongoing use of the framework.

Control of symptoms Patients’ symptoms and concerns need to be noted and actioned as part of a defined process. An anticipatory approach to prescribing is also essential, particularly out of hours.

Increased involvement of healthcare professionals in the provision of care
The advanced supply of medicines to be used at home if necessary
Increased social care support

Box 1: Professionals involved in palliative care

As well as doctors, nurses, pharmacists and healthcare assistants, the following professions are also among those involved in the provision of effective palliative care:

**Occupational therapy** Occupational therapists work closely with patients and their families to achieve the best possible level of independence for individuals. They provide specialist equipment and recommend environmental adaptations as patients’ physical condition changes.

**Physiotherapy** Physiotherapists can help patients maintain independence using approaches that aim to achieve maximum functional ability and relief from distressing symptoms, such as pain, anxiety, fatigue and breathlessness.

**Dietetics** Dietitians provide support for patients around eating and drinking. This includes ensuring that patients receive optimal nutrition depending on their disease and providing specialist advice for patients with severe swallowing difficulties or who have enteral tubes.

**Social work** Social workers provide advice and support for patients and their families in a number of areas, including financial, legal, housing and emotional concerns. Social issues can have a direct impact on patients’ symptom control and quality of life.

**Continuity** Relevant information (diagnosis, treatment, up-to-date medication list, patient preferences, etc) should be made available to all professionals involved in patients’ care, including out-of-hours staff.

**Continued learning** Those delivering end-of-life care should show commitment to learning and development. Specialist palliative care providers need to play a lead role in delivering education, especially for healthcare assistants (who deliver most of the physical nursing care in care homes).

**Carer support** Meeting the needs of carers is an integral part of high-quality palliative care. Carers’ needs should be assessed and appropriate emotional, practical and bereavement support provided.

**Care in the dying phase** Patients in the last days of life (the terminal phase) must be cared for in line with appropriate protocols and care pathways (see below). Clinicians must consider all aspects of patient and family care at this time, including stopping non-essential medicines and interventions, considering comfort measures, psychological and religious/spiritual support, bereavement planning, communication and care after death.

The GSF minimum protocol is a checklist that clinicians can use when caring for patients in the dying phase. The protocol includes prompts for reviewing medicines, notifying out-of-hours healthcare professionals and agreeing a plan of care and communication.

**Liverpool care pathway**

The terminal or dying phase refers to the last few days of life when a patient may need an increased level of care. The Liverpool care pathway for the dying patient (LCP) is an integrated care pathway that can be introduced at this time to ensure the care received in the final days and
hours of life is of a high standard and consistent across different care settings. It allows the needs of the patient to be identified and addressed appropriately.

Key areas for pharmacist involvement in the LCP include medication review and prescribing medicines for symptom control during the dying phase (see below and accompanying article, p322).

Specialist clinical pharmacist role
Pharmacists working in palliative care can be based in a number of settings, usually hospice, hospital or community pharmacy. Roles vary and can range from supplying specialist palliative care drugs to providing a full clinical service as part of a specialist palliative care team.

At John Taylor Hospice, Birmingham, clinical pharmacist posts form part of a multidisciplinary team that works primarily in the community visiting patients and families in their preferred place of care (usually at home). Patients referred to a clinical pharmacist will have a range of needs and issues, some of which are described below.

Medication review and medicines reconciliation
Patients who benefit the most from medication review tend to be those with multiple co-morbidities who are taking complex drug regimens. Such patients are often managed by a number of different specialists in different areas, without an overarching plan. Medication review is an opportunity to rationalise patients’ medicines and have open discussions with patients, and with carers, about how they take their medicines and their concerns.

Medicines reconciliation is useful in ensuring discrepancies introduced before and after hospital admission are resolved. Performing this in patients’ homes allows more comprehensive assessments to be completed. Adherence issues can be addressed and information given to empower patients to be involved in their care.

Complex symptom control
Patients who respond poorly to conventional first- and second-line therapies, or who have experienced side effects, are often referred to a pharmacist. He or she will take a full clinical history, including the patient’s symptoms, treatments tried, doses used and response to these. Based on this information the pharmacist would then consider all the options available for symptom management — which could include trying a third-line drug, maximising doses of current medicines, using combination therapy, arranging admission to a hospice, referral to an oncology team (eg, to consider palliative radiotherapy), etc.

Impaired drug metabolism or clearance Patients with impaired renal or liver function are commonly referred to a specialist pharmacist. Involvement can range from advice on drug doses to selection of specialist medicines, particularly at the end of life.

Drug administration difficulties Swallowing difficulties are often experienced by patients at the end of life, but can occur earlier in those with head and neck cancer and some neurological conditions. Providing advice on drug choice, formulation and rationalisation of medicines is part of the pharmacist’s role. Understanding different feeding tubes and routes of administration is a key element.

Use of specialist palliative care drugs
There are certain specialist palliative care drugs that are not used routinely in the community (eg, ketamine, methadone, mexitilnatrexone). The clinical pharmacist should have input into decisions to use such medicines, and be involved in monitoring and ensuring safe, ongoing supplies — a particular challenge in the community.

Non-cancer diagnoses
Patients with a non-cancer diagnosis are often referred to a palliative care pharmacist, since other professionals are less familiar with the medicines they are taking. Such patients include those with end-stage heart failure, renal failure, chronic obstructive pulmonary disease, motor neurone disease, liver failure, etc.

Tailoring care
Specialist palliative care pharmacists tailor treatment to suit individual patients, aiming for maximal benefit with minimal complications and always respecting personal views about medicines. Palliative care patients can be complex medically, socially and psychologically, so these factors need to be taken into consideration with any pharmaceutical intervention. It is also important to recognise that not all issues can be resolved and that it may be necessary for pharmacists to manage patients’ or carers’ expectations accordingly.

Advanced communication skills are a fundamental part of the role, since discussions about medicines can provoke strong reactions and difficult conversations about death and dying.

The accompanying article will look in more detail at care for patients in the final days of life (p322).

References