

Commissioner's Guide to NCEPOD Report On The Right Course?

Introduction

Cancer outcomes in children and young people have improved dramatically over the last few decades with over 80% of those diagnosed now being cured of their disease. Of those who die, approximately half will do so from treatment-related complications, many of which are avoidable. Most treatment-related deaths are from bacterial sepsis and should therefore be preventable. Emergency care of cancer patients with infection/sepsis has significant areas for improvement as highlighted in the recent Parliamentary and Health Service Ombudsman report 'Time to Act'. These failings included lack of appropriate clinical assessment, inadequate and/or delays to timely treatment, delays in transfer to critical care, delays in senior medical input and failure to recognise the early warning triggers of deteriorating patients.

In children and young people whose cancer is not likely to be curable, difficult decisions need to be made as to the role of further systemic anti-cancer therapy (SACT). There is an evolving understanding that patients and their families want to pursue therapy directed against the tumour in addition to symptom-directed care right up to the end of a patient's life. Patients and their families will seek out opportunities for cancer-directed therapy with or without the input from their treating oncologist and this means that discussions regarding therapy will continue throughout a patient's care even when a patient is deteriorating from progressive disease. Whether further systemic anti-cancer therapy is appropriate, and balancing its potential benefits with its toxicity, are contentious and topical issues.

This report focuses on a sample of patients who were a high-risk group who died or who had an unexpected admission to intensive care. This is where care-planning, service provision and communication should excel. Any remediable factors in care for this group would benefit all children, teenagers and young adults receiving systemic anti-cancer therapy.

Patient population

The study examined the care of children, teenagers and young adults aged 24 years and under, who died and/or had an unplanned admission to critical care within 60 days of receiving systemic anti-cancer therapy (SACT).

Data from the National Cancer Registration and Analysis Service 2018 report shows 21,289 newly diagnosed cancers registered among children under 15 years of age and resident in England from 2001 to 2015. This works out as a mean of 1,419 new cases per year. The Systemic Anti-Cancer

Treatment Dataset reported data on SACT in people under 24 years of age. 4,400 people received 24,526 cycles between April 2017 and March 2018.

Clinical issues

- Prescriptions were not electronic in around a half of cases reviewed and not checked by a pharmacist in around a sixth
- The routine assessment of performance status of patients before administering systemic anti-cancer therapy was not documented in over half of hospitals
- There was no multidisciplinary team discussion about starting a protocol of systemic anti-cancer therapy for a third of patients
- Clinicians felt under pressure from the patient's family to prescribe systemic anti-cancer therapy in 12% of cases
- Around a half of General Practitioners and Paediatric Oncology Shared Care Units (POSCU) had inadequate information about systemic anti-cancer therapy and the expected toxicities
- Both reviewers and clinicians surveyed found evidence that the intent of treatment was clear in most sets of case notes
- Over 80% of consent forms stated the risk/benefit of systemic anti-cancer therapy or the chances of cure. Fewer than half contained the information that systemic anti-cancer therapy could be life threatening.
- A formal assessment of toxicity of the last systemic anti-cancer therapy cycle was performed in over half of patients
- Assessment of disease response was found in two thirds of cases reviewed. More than half of these were not responding to treatment and in the opinion of the reviewers only half of these should have received further systemic anti-cancer therapy.
- There was evidence in two thirds of cases that patients and their families had received adequate training in the management of febrile neutropaenia
- There was little evidence of parents and patients receiving written information about toxicity or chances for care
- Discussions of ceilings of treatment were documented for fewer than half of palliative care patients and very few end of life care discussions were documented
- Fewer than a fifth of patients were part of a clinical trial
- Patients' vital signs were appropriately recorded for most patients
- 12/19 patients received antibiotics more than one hour following admission

- The reviewers felt that, for those patients admitted to critical care, the admission was appropriate
- On admission to critical care, ceilings of treatment were only in place in 11/60 patients
- Systemic anti-cancer therapy had played a major part in hastening death or the patient died as a direct result of a complication caused by systemic anti-cancer therapy for a fifth of patients
- Most deaths were discussed at an audit or morbidity and mortality meeting in 64/80 cases but the discussion was not always recorded in the case notes

Organisational issues

- Most hospitals were part of a specific cancer network
- Many hospitals in England were yet to adopt electronic prescription of systemic anti-cancer therapy at the time of data collection
- Half of hospitals had no formal policy that systemic anti-cancer therapy prescribed by a pharmacist should be checked by a second pharmacist
- Almost a third of cases reviewed did not have any electronic record of systemic anti-cancer therapy received by a patient
- Non-medical staff could prescribe systemic anti-cancer therapy in over 40% of hospitals
- There were no formal training programmes for pharmacists to prescribe systemic anti-cancer therapy in almost half of hospitals or in the use of electronic prescribing systems in a fifth.
- When a patient is admitted with a complication of systemic anti-cancer therapy to the prescribing hospital, most organisations had a mechanism for informing a named haemato oncologist. If the patient is admitted to a different organisation this fell to 60%
- Almost a quarter of hospitals reported maximum journey times for patients receiving systemic anti-cancer therapy of more than one hour
- Fewer than half of hospitals had a policy for the transition of care from paediatric to adult services
- Systemic anti-cancer therapy toxicity was audited by around half of hospitals and nausea and vomiting was only audited by a quarter of hospitals. Fewer than half of hospitals audited death within 60 days of systemic anti-cancer therapy. Over 60% audited central line complications.
- Almost all hospitals participated in peer review or self-assessment exercises relating to UK cancer standards
- Almost all hospitals had a helpline number for patients. Around a fifth of hospitals, provided advice over the telephone by general rather than specialist staff.
- Most of the children's principal treatment centres had on-site paediatric critical care support

- Over a half of hospitals to which teenage and young adult patients were admitted had separate facilities or protocols for this group
- Critical care was often not represented at multidisciplinary team meetings

Key features of a service

- Part of a cancer network
- New protocols of systemic anti-cancer therapy are discussed at multidisciplinary team meetings in advance of commencing treatment
- Electronic prescriptions for systemic anti-cancer therapy
- A policy for use prior to treatment with systemic anti-cancer therapy, which includes an assessment of 'fitness for systemic anti-cancer therapy' and a formal performance status score. This policy is reviewed as part of the organisation's annual review.
- Discussions about systemic anti-cancer therapy with patients and/or their parents are documented and include:
 - The intent of therapy (curative versus palliative)
 - The chances of cure or the benefits of palliative therapy
 - The risk of toxicity including that systemic anti-cancer therapy can be life threatening
 - Ceilings of treatment in patients with a poor prognosis
- Written information for patients and their families about the potential side effects of systemic anti-cancer therapy, in particular the recognition and management of febrile neutropaenia
- Good communication with General Practitioners and Paediatric Oncology Shared Care Units (POSCU) about the systemic anti-cancer therapy patients receive and the potential toxicities the patient may experience at the time of administration
- A process for checking and validating systemic anti-cancer therapy prescriptions by a suitably trained doctor, nurse or pharmacist, other than the prescriber
- All systemic anti-cancer therapy prescriptions are available on hospital IT systems and all clinicians have easy 'read only' access to them
- Patients in hospital receive appropriate antibiotics within one hour of recognition of sepsis or suspected sepsis
- Ceilings of treatment are discussed with the patient and/or relatives and agreed between the referring clinician and admitting critical care consultant.

- If critical care is not available on-site, robust clinical protocols and pathways must be in place to ensure there is no delay in care of the critically ill patient.
- Local audit of the side effects and outcomes of systemic anti-cancer therapy are undertaken. Action plans and quality improvement goals are made and discussed, with findings reported at Board level.
- A policy requiring all clinicians involved in the care of oncology patients to undertake morbidity and mortality reviews and attend morbidity and mortality meetings. This should also include the completion of an attendance log.
- A person-focused policy for the transition of oncology care between paediatric, teenage and young adult and adult teams. This should be reviewed as part of the organisation's annual review.

National guidance and reports

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