On the Right Course?

A review of the quality of care provided to patients aged 24 years and under who were receiving systemic anti-cancer therapy and subsequently died or were admitted to critical care.

Executive summary

This analysis of care delivered to children and young adults who either died or had an unexpected admission to critical care within 60 days of receiving systemic anti-cancer therapy SACT has shown a mixed picture.

Overall 58% of patients were thought to have good care and there were many areas of excellent practice. However, in 22% of this high risk group the SACT was directly responsible for death or admission to critical care or had a major role in the outcome. In a further 25% substantial toxicity was observed.

The decision to start SACT is a really important one but in a third of patients (50/148; 33.8%) there was no discussion in a properly constituted multidisciplinary team meeting. Patients and families need frank discussions about the potential risks and benefits, but a fifth (23/131; 17.6%) of consent forms did not state the chances of the treatment being of benefit and in under half (37/85) was there any mention that SACT could be life threatening. There was evidence that doctors felt under pressure from families to prescribe SACT, therefore discussing benefits and risks is of paramount importance and should be addressed by development of a nationally agreed bespoke consent form for SACT in this age group.

Assessing patients before the administration of SACT was variable - essential investigations were done in almost all patients but assessing disease response, previous toxicity and holistically assessing the patient for their fitness to receive SACT (performance status) was only performed in half (61/123; 51.4%) the patients. These assessments were performed more frequently in patients who were on clinical trials, but only 18% of this study population were on a clinical study for this prescription of SACT due to the fact that they had been selected from a high-risk group of patients often with relapsed or recurrent disease. Almost 70% of the study population had been treated previously with at least one protocol of therapy, therefore a much higher percentage of patients may have been on clinical trials for their front-line therapy. This study highlighted the absence of clinical trials for patients with resistant or recurrent disease and the reviewers, in their discussions, strongly advocated the use of trials in this group as a mechanism of improving patient care. Whilst the data showed that patients in this study were found to have better care when they were on a trial, the study did not have sufficient data to justify a formal recommendation to expand clinical trial availability.

Continued over

Sepsis is a major risk in patients receiving SACT but opportunities to adequately train patients and families in its recognition were not taken in a third of patients.

Open discussions about the appropriateness of intensive care and of ceilings of treatment are always difficult but even in patients who were being treated with palliative intent only, these occurred in a minority. The reviewers were of the opinion that these discussions were better facilitated when the oncology unit and intensive care unit were co-located.

Audit and quality improvement methods, with action plans, are essential for on-going improvement but require access to data. Electronic prescribing was not universal at the time of data collection and many hospitals had no ready access to information on which patients had received SACT and their outcomes. Routine auditing of toxicity of SACT happened in less than half (49/105; 46.7%) and of deaths within 60 days of treatment in only two thirds (46/106; 43.4%).

The recommendations from this report are largely based on factors that can be improved quickly and without large financial implications in terms of structure or equipment. As with many other NCEPOD reports, adequately trained staff, good team working and clear local leadership are key to improving care for this vulnerable population.

Principal recommendations

These recommendations have been selected using a consensus exercise, by all involved with the study, to be the primary action points. They have been taken from the full list of recommendations on pages 61-64.

Ensure that any new protocol of systemic anti-cancer therapy (SACT), to a given patient, is discussed at a multidisciplinary team meeting, in advance of commencing treatment.
(Medical Director, Director of Nursing, Consultants, Pharmacists, Specialist Nurses)

Ensure that discussions about systemic anti-cancer therapy (SACT) with patients and/or their parents are documented and include:
a. The intent of therapy (curative versus palliative)
b. The chances of cure or the benefits of palliative therapy
c. The risk of toxicity including that SACT can be life threatening
d. Ceilings of treatment in patients with a poor prognosis
(Consultants)

A nationally agreed consent form specific for systemic anti-cancer therapy (SACT) should be developed and implemented. It should include:
a. The intent of therapy
b. An assessment of the chance of cure
c. The risk of toxicity and
d. The potential risk of death
(NHS England, Welsh Government, Scottish Government and the Department of Health in Northern Ireland)

Ensure consultant review within 14 hours of an acute admission in line with the Royal College of Paediatrics and Child Health in *'Facing the Future'* and the Royal College of Physicians of London in the *'Acute Care Toolkit 4'*.
(Medical Director, Director of Nursing, Consultants)