Care provided to young patients receiving systemic anticancer therapy

Cancer outcomes for children have steadily improved in recent years with over 80% of newly diagnosed patients now being cured of their disease (National Cancer Registration and Analysis Service, 2018). In patients with acute lymphoblastic leukaemia who die, there may be as many patients where the cause of death is related to treatment with systemic anticancer therapy as is related to the cancer (O'Connor et al, 2014). Most treatment-related deaths are from bacterial sepsis, the treatment of which has been highlighted as requiring improvement in many reports, including in an earlier study undertaken by the National Confidential Enquiry into Patient Outcome and Death (NCEPOD), *Just Say Sepsis* (Goodwin et al, 2015).

For patients whose cancer is incurable, difficult decisions have to be made regarding treatment planning, balancing the benefits of active systemic anticancer therapy with the risk of potentially life-threatening complications which may arise from its administration, sometimes with pressure from the patient and/or the family to continue treatment no matter what. These issues are contentious and difficult, and it is therefore essential that there is ongoing monitoring of the response of the cancer to therapy and the performance status of the patient to inform discussions and decision making throughout the pathway of care.

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The NCEPOD study

On the Right Course? (Michalski et al, 2018) was a study undertaken by NCEPOD reviewing the quality of care provided to cancer patients who died or who had an unplanned admission to critical care within 60 days of systemic anticancer therapy. Patients were identified retrospectively from hospital electronic records in tertiary centres and general hospitals where systemic anticancer therapy was administered and where patients were admitted (unexpectedly) to the intensive care unit and/or died within the study period. Case note extracts were reviewed from the start of the systemic anticancer therapy protocol and the final course of treatment as well as the final admission to hospital (during which the patient died or was admitted to the intensive care unit).

Overall 58% of patients were thought to have had good care and there were many examples of excellent practice. However, in 22% of this high-risk group the systemic anticancer therapy 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.

Initiation of systemic anticancer therapy

The decision to start systemic anticancer therapy is extremely important and should be discussed with the patient and the family. In a third of patients' notes (50/148, 34%) there was no record that a multidisciplinary discussion about the most recent course of systemic anticancer therapy had taken place. Furthermore, the overall intent of the treatment (as palliative or curative) was unclear in 16 out of 145 (11%) sets of case notes.

There was also a lack of clarity in the recorded discussions about the potential risks and benefits of treatment, with 23 out of 131 (17.6%) consent forms not stating the chances of the treatment being beneficial and 37 out of 85 having no mention that systemic anticancer therapy could be life threatening. There was some evidence that doctors felt under pressure from families to prescribe systemic anticancer therapy (19/155, 12.3%) so an informed discussion of benefits and risks is essential. The report recommends that this should be addressed by the development of a nationally agreed, bespoke consent form for systemic anticancer therapy in this age group.

Administration of systemic anticancer therapy and ongoing management

There was variation in the quality of assessment of patients before the administration of systemic anticancer therapy – essential investigations were mostly completed but disease response, previous toxicity and the patient's fitness to receive systemic anticancer therapy (performance status) were only assessed in half (61/123, 51%) the study population.

Electronic records show details of each dose administered throughout the patient's history and allow easy access of data for audit and review or sharing of data between providers. However, in nearly a third (43/141, 31%) of cases reviewed in this study, electronic patient records were not readily available.

Toxicity following last cycle of therapy

Two thirds of patients (80/123, 65%) experienced a common toxicity criteria grade 3 or 4 episode following their final cycle of systemic anticancer therapy. However, in the vast majority of patients (101/107, 94.4%) there were no missed opportunities for earlier intervention in the management of toxicity.

Final admission to hospital

Patients were admitted to hospital as an emergency in 69% (90/130) of cases reviewed and in 38% (32/84) the admissions were out of hours. The care was generally good; in only 7% of cases was there a delay in assessment by a junior clinician and in only 10% of these assessments was there room for

improvement. However, there was a delay in patients being reviewed by a consultant – 12 out of 39 patients did not meet the recommendation of review within 14 hours of admission, as has been put forward nationally (Royal College of Physicians, 2012; Royal College of Paediatrics and Child Health, 2015). Eight of these patients were unwell with significant complications relating to either disease progression or systemic anticancer therapy-related toxicity.

Sepsis is a major risk in patients receiving systemic anticancer therapy and reviewers found that a quarter of patients (34/133, 25.6%) had signs of sepsis on admission to hospital. However, 12 out of 19 patients with suspected sepsis received antibiotics more than 1 hour following admission, contrary to national guidance (National Institute for Health and Care Excellence, 2017). The importance of early delivery of antibiotics in the sepsis pathway was highlighted in an earlier NCEPOD report as well as others (Goodwin et al, 2015).

While it is recognized that discussions about the appropriateness of intensive care and about ceilings of treatment are complex and difficult, it was noted that even for patients who were being treated with palliative intent, these discussions did not regularly occur. Only 37 out of 68 cases reviewed had evidence of any discussion between the referring clinician and the intensivist. Ceilings of treatment were documented in only in 11 out of 60 sets of case notes.

Organizational factors

Audit and quality improvement methods, with action plans, are essential for ongoing improvement but require access to data. Electronic prescribing was not universal at the time of data collection and many hospitals did not have readily available access to information on which patients had received systemic anticancer therapy and their outcomes. Routine auditing of toxicity of systemic anticancer therapy happened in 47% (49/105) of hospitals and of deaths within 60 days of treatment in only 43.4% (46/106).

Similarly, in only 64 out of 80 cases was the patient's death discussed in mortality and morbidity meetings and in only 9% (9/105) of hospitals did intensivists routinely attend oncology mortality and morbidity meetings. A joint approach between oncology and intensive care would facilitate some of the discussions that were lacking in the patients reviewed in this study.

The study population comprised patients aged 0–24 years, so included patients who may be transitioning from paediatric to adult services. However, only 33 out of 77 hospitals had a policy for the transition of patients from paediatric to adult services.

Conclusions

The report recommendations are largely based on factors that can be improved easily and quickly without large financial implications in terms of services or equipment. As with many other NCEPOD reports, adequately training staff to carry out good basic medical practice, and ensuring good communication, team working and clear local leadership are key to improving care for this vulnerable population. **BJHM**

KEY POINTS

- In one third of patients, the initiation of systemic anticancer therapy was not discussed in a multidisciplinary team meeting.
- There was a lack of clarity around the discussions to initiate a course of systemic anticancer therapy including the intent of treatment, the chance of cure, risk of complications or death.
- Before administration of systemic anticancer therapy, routine assessment of efficacy of treatment and performance status of the patient was only completed in half the study population.
- Patients admitted to hospital with complications of systemic anticancer therapy sometimes did not see a consultant within 14 hours of admission and nearly half of those with signs of sepsis on arrival did not receive antibiotics within 1 hour.

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