Abstract

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Palliative Care in Teenage and Young Adult Cancer: What Does Good Look Like?

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ABSTRACT

Introduction and Aims: Cancer is a leading cause of death in teenagers and young adults (TYAs), yet current national guidelines provide no TYA-specific palliative care (PC). TYAs are managed under adult or paediatric services, neither of which address their unique developmental needs. This project evaluated national guidelines and clinical practice in TYA PC and explores TYA perspectives on holistic service provision.

Methods: A gap analysis compared adult and paediatric PC guidelines. A service evaluation of TYAs aged 16-24 years with a palliative cancer diagnosis was conducted, with thematic analysis mapped to guidelines. These patients were included in a complex symptom audit. Findings informed creation of a novel survey exploring TYA priorities for PC discussions.

Results: Nine patients were included in the service evaluation. Guidelines highlight care planning, discussing prognosis and family support, however, these were inconsistently addressed within practice. Fertility, sexuality, psychosocial and identity concerns and care continuity were frequently accessed but absent in current guidelines. Symptom audit showed TYAs most frequently require PC support for pain (73%), nausea/vomiting (24%), EOL care (12%) and bowel disturbances (9%). Survey responses highlighted poor patient understanding of PC and strong preferences for early, honest and independent discussions on care planning, mental health, and sexuality.

Conclusions: A disconnect exists between professional understanding and patient priorities in TYA PC. This may reflect limited research, lack of TYA involvement in service planning and insufficient training and confidence among professionals and families. Findings provide exploratory evidence justifying guideline reform and further research into TYA-specific PC.

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