

The role of Primary Care in the management of Teenagers and Young Adults with Cancer: a qualitative study.

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BACKGROUND

- TYA with cancer (TYAC)
 - Rarely seen in Primary Care
 - Unique profile
 - Incidence and survival increasing
- Lack of evidence for optimal care throughout the cancer journey

AIMS

- Define GPs' experiences of looking after 15-24 year olds with cancer
- Understand benefits and barriers to primary care involvement (throughout the cancer journey)

QUESTIONS

- How can we best support TYA patients through their cancer journey, and beyond?
- Is disappearance from primary care a problem for GP-patient relationship?
- What is the role of GPs in TYAC care?
- Are there unique aspects of TYAC care that need to be addressed to improve care?

METHODS

Purposive Sample (n=56) of GPs of 15-24 year old cancer patients approached
Sources: TYA MDaT database, ON TARGET programme, professional recommendation

Data collection - interviews with 11 GPs
 Audio recorded, semi-structured interview format
 Utilised topic guide developed by TYA experts based on real cases

Analysis
 Thematic, utilising constant comparative method
 Subset independently read

TOPIC GUIDE

- Previous TYAC experience
- Patient relationship with GP
- Patient involvement with primary care
- Family members role / characteristics
- Communication with secondary care
- GP perception of role offered

SAMPLE CHARACTERISTICS

- 6 Male, 5 Female GPs
- 6 had some TYAC interest or experience
- 15 cases aged 15-23 years discussed: 11 female
- Diagnoses included: leukaemia, lymphoma, CNS tumour, bone & soft tissue sarcoma, gynaecological and thyroid cancer

"She was having so much in the way of input from secondary care I thought, 'Have I got anything to add?'...[I] presumed that she knew we were there all along to support"

"So I think it's probably expecting...that GPs should be part of it, and, how we can achieve that and work together better so we're seen as part of the team of that person going through their journey"

"I don't think that we should necessarily have more involvement with patients coming to see us but I think we should be more aware of what's going on"

FINDINGS

GP role explored:

- Mainly at diagnosis and after treatment
- Variable support offered, including some palliative care

Factors limiting GP involvement:

- **Patient related:**
 - limited prior relationship
 - variable attendance
 - perceived that GP was not involved
 - family dynamic, influence of relatives
- **GP related:**
 - limited knowledge of TYAC
 - concern about burdening patients during treatment
- **Secondary care related:**
 - Delayed or inadequate communication
 - Lack of clarity about future plans

Key points

Working with TYAC is challenging
 GP role is unclear
 Interviews prompted reflection

Limitations

Sample size
 GP perspective only

Next Steps

Explore primary-secondary care relationships
 Interview patients, families, specialists and GPs

Further work to support engagement of GPs is required but effective communication and clear information for GPs and patients at diagnosis and during/after treatment could help clarify expectations, prevent disruption of the patient : primary care relationship and assist them in contributing to the management of TYA with cancer.