Using participatory research to describe young people's experience of cancer care

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Introduction

It is recognised that teenagers and young adults (TYA) are caught between two worlds: childhood and adulthood. Nowhere is this contrast more apparent than when accessing healthcare services, especially cancer services, which are traditionally designed for children or older adults and fail to meet the age specific psychosocial needs of young people.

Health policy in England now recognises these needs¹ with key recommendations suggesting unhindered access to age-appropriate care and access to a broader range of TYA professional expertise. However, there is little research exploring young people's experiences of cancer care.

Methods

TEENAGE CANCER TRUS

The CCG conducted semi-structured peer interviews with young people, which were digitally recorded. On completion of the interview, young people extrapolated a headline which reflected their story. Each headline was explored in more depth through group discussion.

Data were analysed through group analysis of the interview transcripts and rudimentary thematic analysis based on the headlines.

Aims

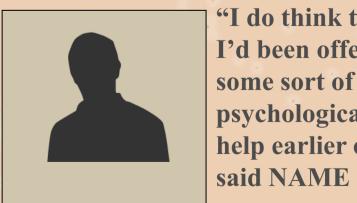
The aim of this study was to explore, using participatory methods with the NCRI TYA Core Consumer Group (CCG), young people's perceptions and experiences of cancer care.

Findings

Eleven young people diagnosed with cancer aged 14 – 25 years attended a one-day workshop (4 CCG and 7 participants). Participants were between six months and five years post treatment from a range of commonly occurring cancers in TYA. Young people's experiences of care included paediatric, adult and specialist TYA cancer units. Eight core themes emerged from the interviews, which are presented below using young people's headlines. Pseudonyms were chosen by the CCG.



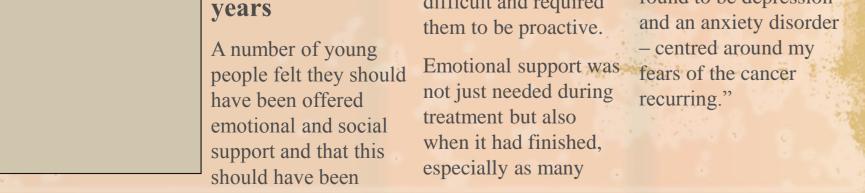
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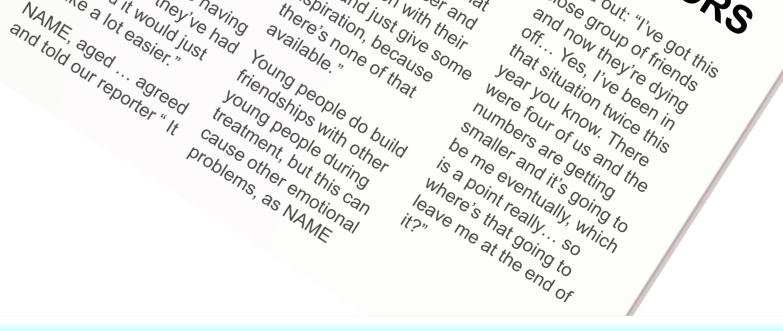
"I do think that it offered with the same young people developed other health priority as physical I'd been offered problems. care. Young people who had NAME told us "it was psychological experienced emotional roughly around 13 help earlier on" months after finishing difficulties recalled the treatment that... I later said NAME ... quest for help being found to be depression difficult and required

Conclusions

Young people's experiences of cancer care



were varied and complex, incorporating may factors. These insights are important for future service developments and will inform a proposed five-year longitudinal study evaluating specialist TYA cancer care.



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References

¹ National Institute for Health and Clinical Excellence. Guidance on cancer services: Improving outcomes in children and young people with cancer. London: NICE 2005





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