

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

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.



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

Acknowledgements

We would like to thank Teenage Cancer Trust for funding the 'Essence of Care' project, the members of the NCRI TYA CCG for being such conscientious and enthusiastic researchers and finally, to all the young people who have taken part in this and other aspects of 'Essence' – Thank you.