Young people’s priorities for a teenage and young adult specialist cancer unit

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Introduction
Health policy in England recognises the needs of teenagers ad young adults (TYA) with cancer. Key recommendations reflect the age specific needs and unhindered access to age-appropriate environments. Recommendations are made in the absence of a definition of what an age appropriate environment is. Furthermore, little research exists about TYA preferences of key features of an age appropriate environment.

Aims
To identify the priorities for a specialist TYA cancer unit.
To invite TYA who have experienced cancer to work as co-researchers.

Study design
This was a mixed methods study with data generated from two sources: an interactive workshop and a survey.

Study 1
Young people were recruited through Teenage Cancer Trust Facebook page and Jimmyteens.tv to attend a one day workshop.
15 core characteristics of specialist TYA cancer care were identified from the literature and placed on cards.
In two groups, young people ranked the cards through consensus on a pyramid (most important at the top, least important at the bottom).
Spare cards were provided so young people could substitute the pre-printed cards for other features they thought were more important.
Notes were made of the discussions between young people about card placement.

Results
Eleven young people diagnosed with cancer aged 14 – 25 years participated in the workshop.
An example of one pyramid is shown in Figure 2.
The top 3 priorities were:
1. Dedicated unit (“we are treated like adults but we get the privileges and time that other children do”).
2. Young people wanted the cancer unit to be like home (carpets not wooden floors), with a mixture of side rooms and bays (ways of ensuring privacy), and an outdoor space that was not populated by smokers (“fresh air does the world of good”).
3. Contact with peers.

Study 2
Young people who attended ‘Find Your Sense of Tumour’ (FYSOT) were given an self-report version of the cards & pyramid (Figure 1).
The completed cards were returned to the NCRI TYA Core Consumer Group (CCG).

Analysis
Cards were ranked within the pyramid.
They were scored from 1 – 5 based on the position in the pyramid (5 points for items at the top down to 1 point for those at the bottom).
A rank score was calculated for each item.
Scores were standardised through dividing by the sample size.
Data for the workshops and FYSOT survey were integrated through ranking the final standardised scores.

Results

Integrated results
Overall, the top ten priorities of a specialist TYA cancer unit were:
1. Dedicated unit.
2. Contact with peers.
3. Somewhere to be alone.
4. Somewhere to go other than bed.
5. Facilities for normal adolescent pursuits.
6. Area were inpatients can meet outpatients.
7. Contact with peers.
8. Access to information
10. Access to expertise (the MDT).

Conclusions

References

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