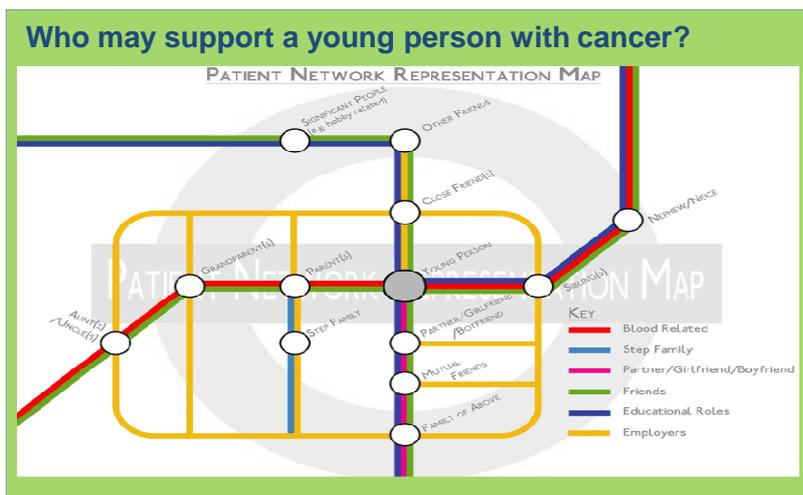


Improving the cancer experience and Aftercare of Teenage and Young Adults (TYA) patients by responding to their supporters needs

Laura Hartley on behalf of the ON TARGET team, UHBristol NHS Foundation Trust

For the purposes of the ON TARGET programme, the term 'Patient Network' has been agreed as including those defined and identified by the patient whom they consider significant, excluding health and social care professionals.



Needs of the Patient Network
Preliminary assessment suggests that two distinct but interrelated themes need to be explored with this group:

- The support required for their own emotional and practical needs
 - The assistance that networkers need to better help the patient themselves.
- Carey ML et al. Support Care Cancer 2012; 20:991–1010



Method

16 patients agreed to act as 'gatekeepers' distributing questionnaires to members of the own network.

Results

116 questionnaires were made available
28 questionnaires were returned

"I felt the CNS was there for X (patient) and not there to share my worries"

"sometimes I just felt too exhausted myself to be of any help"

"sometimes it has been hard to know what to say to X"

Questionnaire explored three themes:

1. What assistance did those close to TYA patients provide?

93% offered emotional support to the patient
82% offered practical support
26% gave financial support

2. What did they need to best support the patient?

73% would have liked face-to-face guidance from staff
75% needed better advice/information

3. What was the emotional/practical impact on themselves?

42% sought help but 90% indicated a need for more emotional support

CONCLUSIONS

The needs of those in the patient network may be underestimated but, if addressed, may provide further resources for the support of TYA with cancer