Introduction of treatment summaries and holistic needs assessments for teenagers and young adults after cancer treatment in Scotland: a national feasibility study

Edgar AB[1], Davison N[1], Kumar S[1], Wilkie B[1], White J[2]

[1]NHS Lothian, [2]NHS Greater Glasgow and Clyde

Background

Scottish Government recommends that all teenagers and young adults (TYA) treated for cancer, receive a Treatment Summary (TS) and Holistic Needs Assessment (HNA) to aid communication, education, self-management and identify areas of concern. Our study objectives were: i) to determine the feasibility of implementing TS and HNA for Scottish TYA after cancer treatment; and ii) to share the TS with health professionals to improve communication and engagement.

Method

Scottish TYA (16-24 years) completing cancer treatment, between April 2016 -April 2017, were identified at the weekly National TYA Multidisciplinary Team (TYA MDT) meeting. Treatment Summaries (Generic and disease specific) were developed by the clinical team and informed by the Scottish Primary Care Cancer Group and TYA patient representatives, and the HNA tool was The Adolescent and Young Adult Oncology Screening Tool reproduced and adapted with permission from CanTeen. Treatment summaries and HNA were completed and distributed to patients and health professionals.

Table 1. Cancer diagnoses

Cancer (Birch Classification)	Number (N=51)	Percentage
Leukaemias	2	4%
Lymphomas	14	27%
Central Nervous System Tumours	1	2%
Bone Tumours	7	14%
Soft Tissue Sarcoma	1	2%
Germ Cell Tumours	20	39%
Melanoma and Skin Carcinoma	1	2%
Carcinoma (except Skin)	4	8%
Misc. Specified Neoplasms NEC	0	0
Unspecified Malignancies & Other	1	2%

Results

Of 83 eligible patients, 51 were recruited (response rate 61%); 26 (51%) males, median (range) age 22 (16 – 25) years. Among non-recruits: 2 relocated, 1 relapsed, lead consultant deemed the process 'not relevant' (n=6), or did not respond (n=23). Cancer diagnoses (Table 1): germ cell tumours (39%), lymphomas (27%) and bone tumours (14%) over represented; carcinoma (8%), melanoma (2%) and CNS tumours (2%) under-represented.

Of the 51 patients, 45 (88%) were in first remission and six (12%) in second remission. A first line therapeutic clinical trial was available for only five cases (10%), of whom three (6%) were recruited on to a clinical trial. Two patients were recruited onto a translational trial.

As a direct consequence of the project, discussion of TS and HNA at the weekly national TYA MDT was successfully introduced and established as standard practice, highlighting the importance of national collaboration and team working.

Conclusions

Treatment Summaries and Holistic Needs Assessments were completed for almost two thirds of TYA identified after cancer treatment. Recruitment failure was due largely to consultant disengagement. Based on incidence data (180 new TYA cancer cases/year), current pathways do not allow identification of almost half of patients at the end of treatment and certain disease are over represented: reflecting the disease specialties of engaged national TYA MDT members. Completion of TS/HNA is labour intense and adequate time and training must be provided. By sharing Treatment Summaries we have improved communication and engagement with Primary Care and provided clear pathways for referral of patients to hospital when problems arise.

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