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The impact of specialist care on teenage and young adult patient-reported outcomes in England: a BRIGHTLIGHT study

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Keyword:	Anxiety, Depression, Social Support
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Abstract:	<p>Purpose: In England, healthcare policy promotes specialised age-appropriate cancer services for teenagers and young adults (TYA), for those aged 13-24 years at diagnosis. Specialist Principal Treatment Centres (PTC) provide enhanced age-specific care for TYA, although many still receive all or some of their care in adult or children's cancer services. Our aim was to determine the patient-reported outcomes associated with TYA-PTC based care.</p> <p>Methods: We conducted a multi-centre cohort study, recruiting 1,114 TYA aged 13-24 years at diagnosis. Data collection involved a bespoke survey at 6,12,18,24 and 36-months after diagnosis. Confounder adjusted analyses of perceived social support, illness perception, anxiety and depression, and health status, compared patients receiving NO-TYA-PTC care with those receiving ALL-TYA-PTC and SOME-TYA-PTC care.</p> <p>Results: Eight hundred and thirty completed the first survey. There was no difference in perceived social support, anxiety or depression between the three categories of care. Significantly higher illness perception was observed in the ALL-TYA-PTC and SOME-TYA-PTC group compared to the</p>

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	<p>NO-TYA-PTC group, (adjusted difference in mean (ADM) score on Brief Illness Perception scale 2.28 (95% confidence intervals (CI) 0.48 to 4.09) and 2.93 (1.27 to 4.59) respectively, p=0.002). Similarly, health status was significantly better in the NO-TYA-PTC (ALL-TYA-PTC: ADM - 0.011 (95%CI -0.046 to 0.024) and SOME-TYA-PTC: -0.054 (-0.086 to -0.023); p=0.006).</p> <p>Conclusion: The reason for the difference in perceived health status is unclear. TYA who accessed a TYA-PTC (all or some care) had higher perceived illness. This may reflect greater education and promotion of self-care by healthcare professionals in TYA units.</p>

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Manuscripts

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3 The impact of specialist care on teenage and young adult patient-reported outcomes in England: a
4 BRIGHTLIGHT study
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Abstract

Purpose: In England, healthcare policy promotes specialised age-appropriate cancer services for teenagers and young adults (TYA), for those aged 13-24 years at diagnosis. Specialist Principal Treatment Centres (PTC) provide enhanced age-specific care for TYA, although many still receive all or some of their care in adult or children's cancer services. Our aim was to determine the patient-reported outcomes associated with TYA-PTC based care.

Methods: We conducted a multi-centre cohort study, recruiting 1,114 TYA aged 13-24 years at diagnosis. Data collection involved a bespoke survey at 6,12,18, 24 and 36-months after diagnosis. Confounder adjusted analyses of perceived social support, illness perception, anxiety and depression, and health status, compared patients receiving NO-TYA-PTC care with those receiving ALL-TYA-PTC and SOME-TYA-PTC care.

Results: Eight hundred and thirty completed the first survey. There was no difference in perceived social support, anxiety or depression between the three categories of care. Significantly higher illness perception was observed in the ALL-TYA-PTC and SOME-TYA-PTC group compared to the NO-TYA-PTC group, (adjusted difference in mean (ADM) score on Brief Illness Perception scale 2.28 (95% confidence intervals (CI) 0.48 to 4.09) and 2.93 (1.27 to 4.59) respectively, $p=0.002$). Similarly, health status was significantly better in the NO-TYA-PTC (ALL-TYA-PTC: ADM -0.011 (95%CI -0.046 to 0.024) and SOME-TYA-PTC: -0.054 (-0.086 to -0.023); $p=0.006$).

Conclusion: The reason for the difference in perceived health status is unclear. TYA who accessed a TYA-PTC (all or some care) had higher perceived illness. This may reflect greater education and promotion of self-care by healthcare professionals in TYA units.

Introduction

The unique needs of teenagers and young adults (TYA) with cancer have been recognised in England since the 1990s. The Calman Hine report of 1995 first acknowledged the needs of the adolescent with cancer and Teenage Cancer Trust have since provided care in specialist units and funded dedicated staff since that time.¹ In response to increasing evidence that young people experienced poorer outcomes than children and older adults,²⁻⁴ guidance was published in 2005 by the National Institute for Health and Care Excellence (NICE),⁵ recommending that care for those aged 15-18 years be delivered in a TYA Principal Treatment Centre (PTC), and with those aged 19-24 being able to choose care more locally or in a PTC centre but also have “*unhindered access to age-appropriate care*”. A model of care was introduced across England which categorised 13 hospitals as TYA-PTCs. Within the TYA-PTC model, cancer needs were attended to and additionally each TYA-PTC hosted the TYA multidisciplinary team with a specific remit to address young people’s psychosocial needs. Care devolved into a hub and spoke model with the TYA-PTC linking to hospitals in the geographical region, which were designated to deliver some but not all aspects of age-appropriate care (see Taylor et al.⁶, and Cable and Kelly¹ for more detailed description of cancer services for TYA in England). Recommendations in the NICE guidance were implemented across England, with the anticipation that all 13 TYA-PTCs would be in service by 2010. At the release of the Guidance in 2005 there were a number of well-established TYA units already in existence, but many hospitals needed to develop these from scratch, including establishing a TYA workforce, building relationships with the designated hospitals and making predominantly adult cancer services aware of this new recommendation and service. It would take nearly a decade for equitable services to be established.⁶

Despite the huge investment from both the third sector and British Government in TYA cancer services, the recommendations were based on limited evidence specific to TYA.⁷ We obtained funding in 2011 to undertake a comprehensive evaluation of TYA cancer care in England to determine whether specialist care for TYA added value. This National Institute for Health Research (NIHR) funded programme of work examined the places where care was delivered,^{8,9} the people who were delivering care,^{9,10} and the impact on the people who were receiving care.¹¹⁻¹³ The impact on outcome was determined through a longitudinal cohort study. The primary outcome, which was selected by young people, was quality of life. In addition, the bespoke survey included a number of validated outcome measures and study-specific experience questions.¹⁴ These were guided by a conceptual model, which showed that central to young people’s experiences of care were psychosocial aspects as well as physical.¹⁵

We previously reported quality of life to be greatest in those who had no treatment in the TYA-PTC, but improvements over time were more so for young people who had care in the TYA-PTC as well as in child or adult cancer services. However, improvements in quality of life over three years was greatest in those who had all their care in a TYA-PTC.¹² Survival outcomes were similar between all three groups.¹³ To further illuminate the outcomes associated with specialist TYA cancer care, the aim of this study was to explore whether there were differences in patient-reported outcomes other than quality of life. The ‘TYA-ness’ of TYA cancer care includes a workforce who have skills to communicate appropriately with this population, support in maintaining and reintegrating into education and employment and an environment that allows supporters (friends, family and significant others) to remain with the young person as they progress through treatment. This support is not widely available to young people in children or adult cancer units. We therefore hypothesised that young people who received a greater proportion of care in a TYA-PTC would have more social

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3 support, lower levels of anxiety and depression, less perceived threat of illness and better health
4 status in the first three years after diagnosis.
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6 7 **Methods**

8 9 **Participants and setting**

10 Recruitment methods and characteristics of the BRIGHTLIGHT cohort are reported in detail
11 elsewhere.^{16,17} In summary, the cohort comprised on 1,114 young people aged 13-24 years, newly
12 diagnosed with cancer (ICD-10 codes C00-C97) within four months of diagnosis. Exclusion criteria
13 included: young people not anticipated to be alive at 6-months after diagnosis, receiving a custodial
14 sentence or unable to complete a survey (no restrictions were made for language or sensory
15 impairment that impacted communication). Young people were recruited from 97 hospitals across
16 England between October 2012 and April 2015.
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19 20 **Data collection**

21 Patient-reported data were collected from young people through the BRIGHTLIGHT Survey, a
22 bespoke survey containing five validated questionnaires and 169 questions related to experience
23 and delivery of care, communication and coordination of care, education, employment, wellbeing
24 and relationships.¹⁴ The survey was administered through face-to-face interviews in young people's
25 home by an independent research company at the first time point (wave 1: 6-months after
26 diagnosis) and either online or telephone interview at 12, 18, 24 and 36 months after. Quality of life
27 was the primary outcome for the study, which is reported elsewhere.¹² This paper reports data from
28 the other four validated questionnaires.
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31 32 *Social support*

33 Social support was measured using the Multidimensional Scale of Perceived Social Support
34 (MSPSS), which has domain scores for support by friends, family and significant others plus a total
35 support score.¹⁸ The MSPSS contains 12 statements rated on 7-point Likert scale. The total support
36 score is an average ranging from 1 to 7. The higher the score, the higher the perceived social
37 support. Total scale scores 1–2.9 are considered low support; a score of 3–5 is considered
38 moderate support, and scores from 5.1 to 7 are considered high support.
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41 42 *Illness perception*

43 Illness perception was measured using the Brief Illness Perception Scale (BIPS), which measures
44 the emotional and cognitive representations of illness.¹⁹ It contains eight questions with fixed
45 response scale specific for each question, for example, 'not at all helpful' to 'extremely helpful'. Each
46 question represents a different dimension of illness perception: consequence, personal control,
47 treatment control, timeline, identity, coherence, emotional representation and concern. Responses
48 are scored from 1 to 10, with higher scores for greater perceived illness impact. A total score is
49 calculated through the sum of scores for eight questions, with a maximum score of 80 representing
50 the highest impact of illness. The timeline question was not included in the current study so the sum
51 of seven questions is presented with a maximum score of 70. Combining illness perception items in
52 this way is considered acceptable if there is high internal consistency. For the BRIGHTLIGHT
53 cohort, Cronbach's alpha values were >70% showing acceptable internal consistency.
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57 58 *Anxiety and depression*

59 The Hospital Anxiety and Depression Scale (HADS) was used to measure anxiety and depression.²⁰
60 It contains 14 items scored on a four-grade scale (0–3). Summary scores are calculated for

depression and anxiety, ranging from 0 to 21. Scores of 8–10 are defined as borderline and 11 and over are considered moderate/severe anxiety and depression.

Health status

Health status was measured using the EuroQol-5 Dimension (EQ-5D) 3-level version.²¹ This comprises five dimensions (mobility, self-care, usual activities, pain/discomfort and anxiety/depression) scored on three levels (no, some and severe problems). The EQ-5D visual analogue scale records self-reported health on a vertical scale ranging from 'best imaginable health state' to worst imaginable health state', which was not used in this analysis. Analysis with population norms²² give a utility score ranging from 0 to 1, with 0 representing death and 1 representing perfect health (negative scores represent a health state worse than death).

Analysis

Analysis was carried out following a predefined statistical analysis plan using STATA version 15. A scale, described in detail previously¹⁷, categorised young people as receiving all (100%) their care in a TYA-PTC (ALL-TYA-PTC) compared to no (0%; NO-TYA-PTC) or some (~~1-99%; SOME-TYA-PTC~~) care in a TYA-PTC and ~~the rest~~care in a child or adult cancer centre (~~1-99%; SOME-TYA-PTC~~). This was based on the number of admissions as an in-patient in the first 12 months after diagnosis, calculated through routinely collected National Health Service Hospital Episode Statistics (HES) data. Mixed effects models were used to investigate the relationship between the categories of TYA care and social support, illness perception and HADS scores, allowing for repeated measurements taken over the 3-years since diagnosis. Logistic regression models were used for analysis of HADS caseness. Based on the causal diagram in the form of a Directed Acyclic Graph (DAG) to identify all relevant confounders used in previous analysis,¹² models were adjusted for age at diagnosis, type of cancer (leukaemia, lymphoma, brain and central nervous system, bone tumours, sarcoma, germ cell, melanoma, carcinomas, other), socioeconomic status (Index of Multiple Deprivation (IMD) quintile),²³ severity of cancer (least, intermediate, most),¹² ethnicity (white, other), choice offered about where to receive treatment (yes/no), presence of any long term condition prior to cancer (yes/no), days from first symptom to diagnosis and number of General Practitioner visits before diagnosis. Geographical location (specified as 12 cities, derived from the TYA-PTC and their network of hospitals) was included in the model as a random effect. Models were extended to include interaction terms to investigate predefined subgroup effects by age at diagnosis (both as a continuous factor and using categories of 13-18 and 19-24 years) and tumour type (haematological and solid tumours).

To investigate whether the relationship between scores and TYA category changed over time since diagnosis (measured in days), interaction terms were added to the models. Assumptions of all models were checked. For outcomes where non normality of residuals was a concern a sensitivity analysis was conducted based on quantile regression with robust standard errors²⁴ (Supplemental file Table S1).

Results

BRIGHTLIGHT survey data at wave 1 (6-months post diagnosis) were available for 830 (75%) participants of whom 769 (93%) could be linked to inpatient HES data and categorised on our TYA scale. Details of participation at each wave of data collection are presented in detail elsewhere (Taylor et al.).¹⁷ The demographic characteristics and summary of variables adjusted for in the

analysis are shown in Table 1. Young people in the NO-TYA-PTC group were slightly older, were working part/full time, were married/cohabiting, had less severe disease and a better prognosis.

Social support

The changes in mean perceived social support scores since diagnosis are shown in Figure 1. This illustrates that social support was perceived as low (<3) by all respondents irrespective of place of care from 6-months through to 3-years post diagnosis. From 12 months after diagnosis average social support score in the NO-TYA-PTC group was lower than in the ALL-TYA-PTC and SOME-TYA-PTC groups, but in adjusted analyses there was no statistical evidence of a difference over 3-years. (Table 2; Supplemental file Table S1) and no evidence that the relationship between social support score and level of care changed over time (interaction term $p=0.14$). A sensitivity analysis using quantile regression provided similar results and conclusions (Supplemental file Table S1).

Illness perception

Figure 2 shows mean illness perception scores over time since diagnosis according to level of care. This illustrates a general tendency for improvements in illness perception over time and consistently lower illness perception scores in the NO-TYA-PTC group compared with the SOME-TYA-PTC and ALL-TYA-PTC groups. From adjusted analyses, differences between groups were statistically significant ($p=0.002$); average scores were 2.93 (95% Confidence Interval (CI) 1.27 to 4.59) units higher with SOME-TYA-PTC care and 2.28 (95% CI 0.48 to 4.09) units higher for ALL-TYA-PTC care compared with the NO-TYA-PTC group (Table 2). There was also some weak evidence that the relationship between illness perception score and category of care changed overtime (interaction term $p=0.08$).

Anxiety and depression

Changes in mean anxiety and depression scores over time are shown in Figures 3 and 4. After adjustment for confounding, differences in mean anxiety scores between the SOME-TYA-PTC, ALL TYA-PTC and NO-TYA-PTC groups were small (Table 2). In a model extended to include an interaction with time, there was no evidence that the relationship between TYA-PTC group and anxiety changed over time (interaction term $p=0.25$). There was some evidence of an association between depression score and category of care. Differences in means estimated from the adjusted analysis were small but positive, such that those receiving SOME-TYA-PTC care had more depression than those receiving NO-TYA-PTC care; these were higher on average by 0.57 points (95% CI 0.05 to 1.09). In a model extended to include an interaction with time, there was also some evidence that the relationship between category of care and depression scores changed over time (interaction term $p=0.05$) with larger differences between groups at earlier time points from diagnosis (Figure 4).

Cases of anxiety (scores ≥ 8) ranged from 40% to 33% in wave 1 and 5 in the NO-TYA-PTC group, 39% to 29% in the SOME-TYA-PTC group and 41% to 26% in the ALL-TYA-PTC group and were not statistically significant in adjusted analyses (Supplemental file Tables S2 and S3). Cases of depression (scores ≥ 8) ranged from 21% to 14% between wave 1 and 5 in the NO-TYA-PTC group, 22% to 7% in the SOME-TYA-PTC group and 24% to 13% in the ALL-TYA-PTC group (supplemental file Table S4). In adjusted analysis there was no evidence that depression caseness differed between the categories of care ($p=0.43$; Supplemental file Table S5).

Health status

Changes in health status are shown in Table 3. There is evidence in the adjusted analysis that there was a difference in health status between the SOME-TYA-PTC, ALL-TYA-PTC and NO-TYA-PTC (Table 2; $p=0.002$). Compared to the NO-TYA-PTC group the average scores are lower in the ALL-TYA-PTC and SOME-TYA-PTC groups by -0.01 (95% CI -0.05 to 0.02) and -0.05 (95% CI -0.09 to -0.02) units, respectively (Table 2). Sensitivity analysis was conducted because the utility score (and model residuals) had a non-symmetric distribution. An adjusted quantile regression with robust standard errors was fitted (Supplemental file Table S6) and gave similar estimates; compared to the NO-TYA-PTC group, difference in medians for ALL- and SOME- categories respectively, were: -0.01 (95% CI -0.05 to 0.03) and -0.04 (95% CI -0.08 to -0.01); $p=0.06$).

Discussion

Our study has provided more insight into the outcomes associated with specialist TYA cancer care. We found that social support was initially perceived as low across all categories of care but gradually increased over the three-year study period. This suggests that as young people progressed through their cancer journey, they felt more supported, which could be attributed to the development of stronger connections with healthcare providers, peers, and family members over time. There was no difference according to the place of care, but this may be due to the measure of social support focusing on friends, family and significant others¹⁶ and not specifically about support provided by the healthcare team. This is supported by previous work showing young people do not share their emotions with family at the time of diagnosis as a way of protecting them.²⁵ Future work should use a more specific healthcare support measure to capture the unique support provided by the healthcare team.

One intriguing finding is the high illness perception reported by young people at the first time point, which gradually reduced over the study period. Surprisingly, this perception was significantly lower for young people who had no access to specialist care. The shifting perspective model postulates patients move from having illness in the foreground to wellness in the foreground as part of their recovery.²⁶ This leads to an interesting hypothesis that rather than being a negative perception, retaining a level of illness in the foreground may be indicative of higher health literacy in those with access to specialist care. It is possible that age-appropriate communication delivered by healthcare professionals in specialist TYA cancer care empowered young people to have greater awareness and knowledge of their physical health.^{9,10} This notion is supported by the fact that they rated their health status as poorer, which again, rather than being perceived negatively, might be due to their increased health literacy and self-awareness.

Our study also found that anxiety and depression were higher at 6-months after diagnosis but remained below the threshold for caseness (≥ 8).²⁷ Young people who received care in both a specialist TYA unit and a child/adult cancer unit had slightly higher depression scores compared to those who had no care in a TYA unit. One plausible explanation for this observation could be that young people referred to TYA units may have had more complex diseases requiring specialised expertise. The possibility of prolonged routes to diagnosis may have also contributed to higher levels of anxiety and depression although we found no differences in the times to diagnosis and categories of care (i.e., there were similar times to diagnosis across all three categories of care).²⁸ While this study adjusted for certain diagnostic intervals, other intervals not accounted for might have influenced these outcomes such as time from symptom onset to first consultation with a specialist. We have no information on the reasons why some young people were initially referred to NO-TYA-PTC or TYA-PTC care, but for some groups this may be based on cancer types (sarcoma

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3 and brain tumours as examples). Following referral to a non-TYA-PTC some young people may
4 have ended up in the SOME-PTC group due to worsening disease or psychological status which
5 may have influenced the findings. It is also important to consider psychosocial factors in the
6 decision to refer young patients to TYA units, as the driver for referral may not always be solely
7 based on cancer diagnosis.
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10 Regarding the impact of specialist TYA care on anxiety and depression, our study suggests that
11 receiving care in TYA units might lead to a greater reduction in these psychological issues
12 compared to those without access to such specialised care. This might be attributed to increased
13 access to psychological support, provided either formally through psychology services or informally
14 through youth support workers and nurse specialists with a lower caseload than those in adult
15 services. The psychosocial impact of cancer in young people has been well-documented, with
16 previous studies showing greater psychological distress in young people compared to children with
17 cancer.²⁹⁻³² This represents a period of heightened susceptibility to developing mental health
18 disorders, with over 60% presenting before the age of 25.³³ While the study adjusted for existing
19 long-term conditions, it did not consider the number of co-morbidities, which have been shown to
20 account for self-reported health status.³⁴ Future research should explore the relationship between
21 co-morbidities and psychosocial well-being in young cancer patients.
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26 The current study has a number of limitations as reported in our previous studies looking at the
27 impact of categories of care.^{12,13} This includes: the definition of specialist care based on the TYA-
28 PTC model as described in the NICE guidance⁵ rather than categories better reflecting age-
29 appropriate care;³⁵ the sample only including a fifth of young people diagnosed within the
30 recruitment period; and potential for bias through multiple modes of survey administration. There is
31 an international drive for specialist TYA care, but rigorous evaluation of its benefits remains limited.
32 While some studies have indicated survival benefits with specialist care (not necessarily TYA-
33 specific),^{13,36-38} there is a paucity of research on the patient perspective. Despite these limitations,
34 our study contributes to the growing body of evidence that is necessary to justify specialist services
35 for TYA.
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40 In conclusion, our findings did not support our hypotheses that young people who accessed
41 specialist care would have more social support, lower levels of anxiety and depression, less
42 perceived threat of illness and better health status in the first three years after diagnosis. However,
43 the findings of our study emphasise the importance of social support and psychosocial interventions
44 in the care of young people with cancer. Specialist TYA cancer care appears to play a crucial role in
45 addressing the unique needs of this age group, promoting health literacy, and providing access to
46 psychological support. However, further research is needed to better understand the specific factors
47 that contribute to the observed outcomes and to evaluate the long-term impact of specialist TYA
48 care on the well-being of young cancer patients. Such knowledge can guide the development of
49 comprehensive and tailored care approaches to enhance the overall quality of life and experiences
50 of young people facing cancer.
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53

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60

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2
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6
7

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11
12

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19
20

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25 Chase Farm Hospitals NHS Trust; Keith Elliott, Barnsley Hospital NHS Foundation Trust; Leanne
26 Smith, Blackpool, Fylde and Wyre Hospitals NHS Trust; Shirley Cocks, Bolton NHS Foundation
27 Trust; Victoria Drew, Bradford Teaching Hospitals NHS Foundation Trust; Elizabeth Pask, Central
28 Manchester University Hospitals NHS Foundation Trust; Anne Littley, Central Manchester University
29 Hospitals NHS Foundation Trust; Mark Bower, Chelsea and Westminster Hospital NHS Trust; Scott
30 Marshall, City Hospitals Sunderland NHS Foundation Trust; Lorna Dewar, Colchester Hospital
31 University NHS Trust; Nnenna Osuji, Croydon Health Services NHS Trust; David Allotey, Derby
32 Hospitals NHS Foundation Trust; Karen Jewers, East Lancashire Hospitals NHS Trust; Asha Johny,
33 Gloucestershire Hospitals NHS Foundation Trust; Nicola Knightly, Great Western Hospitals NHS
34 Foundation Trust; Robert Carr, Guy's & St Thomas' Hospital NHS Foundation Trust; Alison Milne,
35 Hampshire Hospitals NHS Foundation Trust; Claire Hall, Harrogate and District NHS Foundation
36 Trust; James Bailey, Hull and East Yorkshire Hospitals NHS Trust; Christine Garlick, Ipswich
37 Hospital NHS Foundation Trust; Alison Brown, Isle of Wight Healthcare NHS Trust; Carolyn Hatch,
38 Lancashire Teaching Hospitals NHS Foundation Trust; Vivienne E. Andrews, Medway NHS
39 Foundation Trust; Sara Greig, Milton Keynes Hospital NHS Foundation Trust; Jennifer Wimperis,
40 Norfolk and Norwich University Hospital NHS Trust; Suriya Kirkpatrick, North Bristol NHS Trust;
41 Jonathan Nicoll, North Cumbria University Hospitals NHS Trust; Ivo Hennig, Nottingham University
42 Hospitals NHS Trust; Karen Sherbourne, Oxford Radcliffe Hospital NHS Trust; Clare Turner,
43 Plymouth Hospitals NHS Trust; Claire Palles-Clark, Royal Surrey County Hospital NHS Trust;
44 Christine Cox, Royal United Hospital Bath NHS Trust; Yeng Ang, Salford Royal NHS Foundation
45 Trust; Jonathan Cullis, Salisbury NHS Foundation Trust; Daniel Yeomanson, Sheffield Children's
46 NHS Foundation Trust; Ruth Logan, Sheffield Teaching Hospitals NHS Foundation Trust; Deborah
47 Turner, South Devon Healthcare NHS Trust; Dianne Plews, South Tees Hospitals NHS Trust; Julia
48 Jonasi, Southend University Hospital NHS Foundation Trust; Ruth Pettengell, St George's
49 Healthcare NHS Trust; Kamal Khoobarry, Surrey & Sussex Healthcare NHS Trust; Angela Watts,
50 The Dudley Group of Hospitals NHS Foundation Trust; Louise Soanes, The Royal Marsden NHS
51 Foundation Trust; Claudette Jones, The Royal Orthopaedic Hospital NHS Trust; Michael Jenkinson,
52 The Walton Centre for Neurology and Neurosurgery NHS Trust; Nicky Pettitt, University Hospital
53 Birmingham NHS Foundation Trust; Vijay Agarwal, University Hospital Birmingham NHS Foundation
54 Trust; Beth Harrison, University Hospitals Coventry and Warwickshire NHS Trust; Fiona Miall,
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University Hospitals of Leicester NHS Trust; Gail Wiley, University Hospitals of Morecambe Bay NHS Trust; Lynda Wagstaff, Walsall Hospitals NHS Trust; Fiona Smith, West Hertfordshire Hospitals NHS Trust; Sarah Janes, Western Sussex NHS Trust; Serena Hillman, Weston Area Health NHS Trust; Christopher Zaborowski, Yeovil District Hospital NHS Foundation Trust.

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Authorship contribution

Conceptualisation, RMT, JSW, JAB, RF, DPS, FG and LAF; methodology, RMT, JSW, JAB, JAG, RGF, DPS, and LAF.; validation, RMT, JSW, DPS, JAG and LAF; formal analysis, JAB and JAG; data curation, JAB; writing—original draft preparation, RMT, JAB and LAF; writing—review and editing, JSW, JAG, RGF, DPS and FG.; visualization, JAB; supervision, RMT; project administration, RMT; funding acquisition, RMT, JSW, JAB, RF, DPS, FG and LAF. All authors have read and agreed to the published version of the manuscript.

Conflict of Interest statement

The authors have no conflict of interests to declare.

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Table 1: Participant characteristics at Wave 1 (numbers are frequency (%) unless stated otherwise)

Characteristic		NO-TYA-PTC N=275	SOME-TYA-PTC N=305	ALL-TYA-PTC N=189
Age at diagnosis (years)	Mean (Standard deviation)	21.03 (3.02)	19.43 (3.38)	20.00 (3.16)
Gender	Male	147 (53%)	163 (53%)	108 (57%)
Ethnicity*	White	250 (91%)	266 (87%)	160 (85%)
	Mixed	4 (2%)	5 (2%)	4 (2%)
	Asian	15 (5%)	24 (8%)	20 (11%)
	Black	4 (2%)	7 (2%)	2 (1%)
	Other	2 (<1%)	3 (1%)	3 (2%)
Socioeconomic status (IMD quintile)	1 – most deprived	66 (24%)	73 (24%)	34 (18%)
	2	47 (17%)	52 (17%)	32 (17%)
	3	51 (19%)	60 (20%)	37 (20%)
	4	65 (24%)	61 (20%)	40 (21%)
	5 – least deprived	46 (17%)	59 (19%)	46 (24%)
Marital Status		N=248	N=258	N=169
	Married/civil partnership	9 (4%)	8 (3%)	6 (3%)
	Cohabiting	43 (17%)	26 (10%)	18 (11%)
	Single/divorced	196 (79%)	224 (87%)	145 (86%)
Current status	Working full/part time	126 (46%)	70 (23%)	43 (23%)
	In education	60 (22%)	110 (36%)	78 (41%)
	Other work (apprentice/intern/voluntary)	5 (2%)	5 (2%)	6 (3%)
	Unemployed	10 (4%)	11 (4%)	7 (4%)
	Long term sick	39 (14%)	50 (16%)	30 (16%)
	Not seeking work	35 (13%)	59 (19%)	25 (13%)
Type of cancer (Birch classification)	Leukaemia	18 (7%)	47 (15%)	31 (16%)
	Lymphoma	110 (40%)	74 (24%)	70 (37%)
	CNS	9 (3%)	9 (3%)	12 (6%)
	Bone	7 (3%)	57 (19%)	3 (2%)
	Sarcomas	8 (3%)	30 (10%)	13 (7%)

	Germ cell	54 (20%)	55 (18%)	31 (16%)
	Skin	22 (8%)	1 (<1%)	4 (2%)
	Carcinomas (not skin)	41 (15%)	30 (10%)	23 (12%)
	Miscellaneous specified**	5 (2%)	2 (<1%)	1 (<1%)
	Unspecified Malignant	1 (<1%)	0	1 (<1%)
Severity at diagnosis (column %, row %)	Least	200 (73%, 47%)	131 (43%, 31%)	95 (50%, 22%)
	Intermediate	48 (17%, 27%)	79 (26%, 44%)	54 (29%, 30%)
	Most	27 (10%, 17%)	95 (31%, 59%)	40 (21%, 25%)
Prognostic score		N=273	N=304	N=189
	<50%	20 (7%)	58 (19%)	37 (20%)
	50-80%	53 (20%)	122 (40%)	44 (23%)
	>80%	200 (73%)	124 (41%)	108 (57%)
Location***	Birmingham	40 (15%)	57 (19%)	12 (6%)
	Bristol	51 (19%)	32 (10%)	3 (2%)
	Cambridge	12 (4%)	7 (2%)	1 (<1%)
	Manchester	22 (8%)	34 (11%)	11 (6%)
	Merseyside	13 (5%)	9 (3%)	4 (2%)
	East Midlands	15 (5%)	24 (8%)	60 (32%)
	Leeds	19 (7%)	24 (8%)	25 (13%)
	Newcastle	13 (5%)	6 (2%)	24 (13%)
	Oxford	5 (2%)	4 (1%)	7 (4%)
	London	60 (22%)	83 (27%)	10 (6%)
	Sheffield	7 (3%)	9 (3%)	9 (5%)
	Southampton	18 (7%)	16 (5%)	23 (12%)

* Wave 1 data was used with missing values completed using available Public Health England data.

** includes 4 'unclassified' – treated in cancer unit but did not have cancer

***Includes the TYA-PTC and hospitals linked to the multi-disciplinary team at the TYA-PTC; where available based on hospital of diagnosis, for 77 cases based on recruiting hospital

Table 2: Results from mixed effects models investigating the relationship between categories of TYA care received during the first 12 months from diagnosis and patient-reported outcomes over 3-5 years

		Adjusted difference in means*	95% Confidence Interval	P-value
Social support (N=730)				
TYA care category (v NO-TYA-PTC)	SOME-TYA-PTC	0.07	-0.06 to 0.20	0.52
	ALL-TYA-PTC	0.01	-0.12 to 0.15	
Illness perception (N=733)				
TYA care category (v NO-TYA-PTC)	SOME-TYA-PTC	2.93	1.27 to 4.59	0.002
	ALL-TYA-PTC	2.28	0.48 to 4.09	
Anxiety (N=733)				
TYA care category (v NO-TYA-PTC)	SOME-TYA-PTC	0.35	-0.35 to 1.04	0.68
	ALL-TYA-PTC	0.44	-0.31 to 1.19	
Depression (N=733)				
TYA care category (v NO-TYA-PTC)	SOME-TYA-PTC	0.57	0.05 to 1.09	0.06
	ALL-TYA-PTC	0.55	-0.01 to 1.12	
Health status (N=733)				
TYA care category (v NO-TYA-PTC)	SOME-TYA-PTC	-0.054	-0.086 to -0.023	0.002
	ALL-TYA-PTC	-0.011	-0.046 to 0.024	

*Adjusted for time since diagnosis, age at diagnosis, type of cancer, socioeconomic status, severity of cancer, ethnicity, choice about where to receive treatment, long-term condition prior to cancer, days from first symptom to diagnosis, number of general practitioner visits before diagnosis. Missing data is due to missing TYA category and missing data in other covariates

Table 3: Comparison of health status between the three categories of care

	NO-TYA-PTC			SOME-TYA-PTC			ALL-TYA-PTC		
	N	Mean (SD)	Median (IQR)	N	Mean (SD)	Median (IQR)	N	Mean (SD)	Median (IQR)
Wave 1	277	0.81 (0.21)	0.85 (0.73 to 1)	312	0.70 (0.26)	0.73 (0.59 to 0.87)	193	0.78 (0.23)	0.81 (0.69 to 1)
Wave 2	176	0.85 (0.22)	1 (0.80 to 1)	214	0.76 (0.27)	0.80 (0.69 to 1)	124	0.85 (0.21)	0.87 (0.76 to 1)
Wave 3	130	0.85 (0.24)	1 (0.76 to 1)	184	0.71 (0.34)	0.81 (0.62 to 1)	105	0.79 (0.29)	0.85 (0.73 to 1)
Wave 4	128	0.79 (0.31)	1 (0.73 to 1)	148	0.66 (0.38)	0.80 (0.53 to 1)	108	0.76 (0.34)	0.85 (0.69 to 1)
Wave 5	111	0.79 (0.30)	0.85 (0.76 to 1)	157	0.60 (0.43)	0.81 (0 to 1)	92	0.71 (0.37)	0.80 (0.69 to 1)

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Figure 1: Mean social support (MSPSS) score over time since diagnosis (days) (with 95% confidence intervals)

Figure 2: Mean illness perception (BIPS) score over time since diagnosis (days) (with 95% confidence intervals)

Figure 3: Mean HADS anxiety scores over time since diagnosis (days) (with 95% confidence intervals)

Figure 4: Mean HADS depression scores over time since diagnosis (days) (with 95% confidence intervals)

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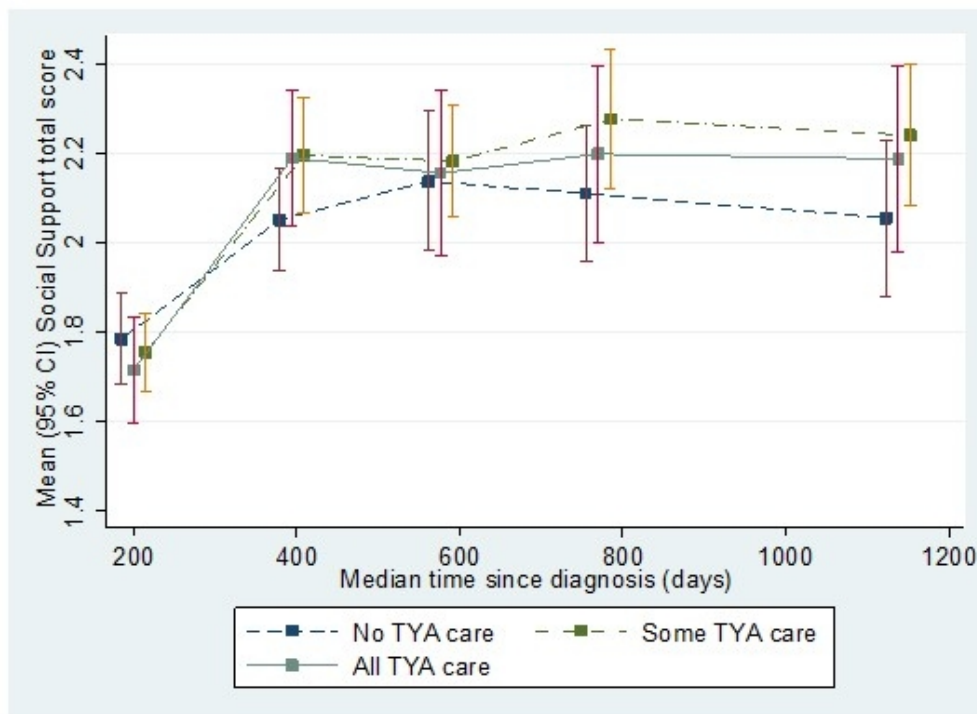


Figure 1: Mean social support (MSPSS) score over time since diagnosis (days) (with 95% confidence intervals)

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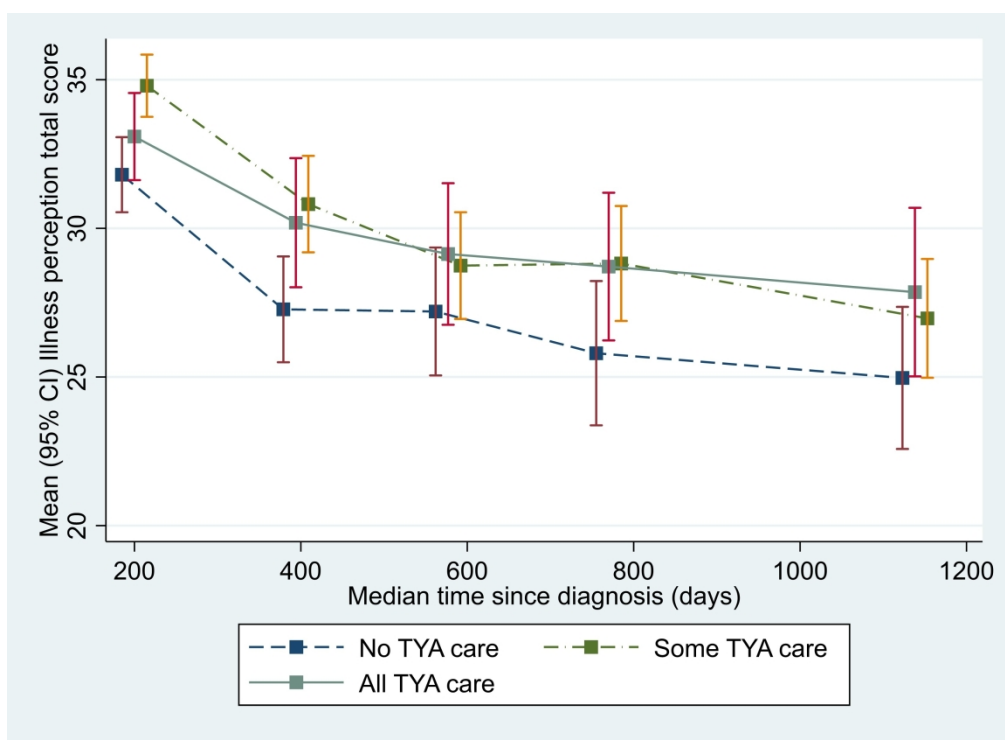


Figure 2: Mean illness perception (BIPS) score over time since diagnosis (days) (with 95% confidence intervals)

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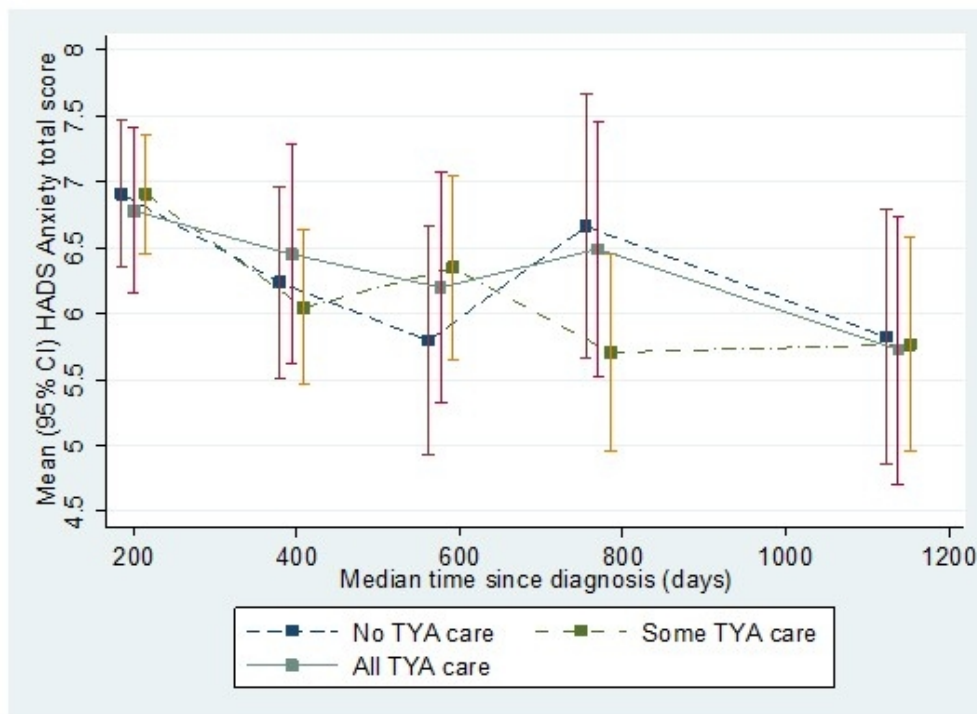


Figure 3: Mean HADS anxiety scores over time since diagnosis (days) (with 95% confidence intervals)

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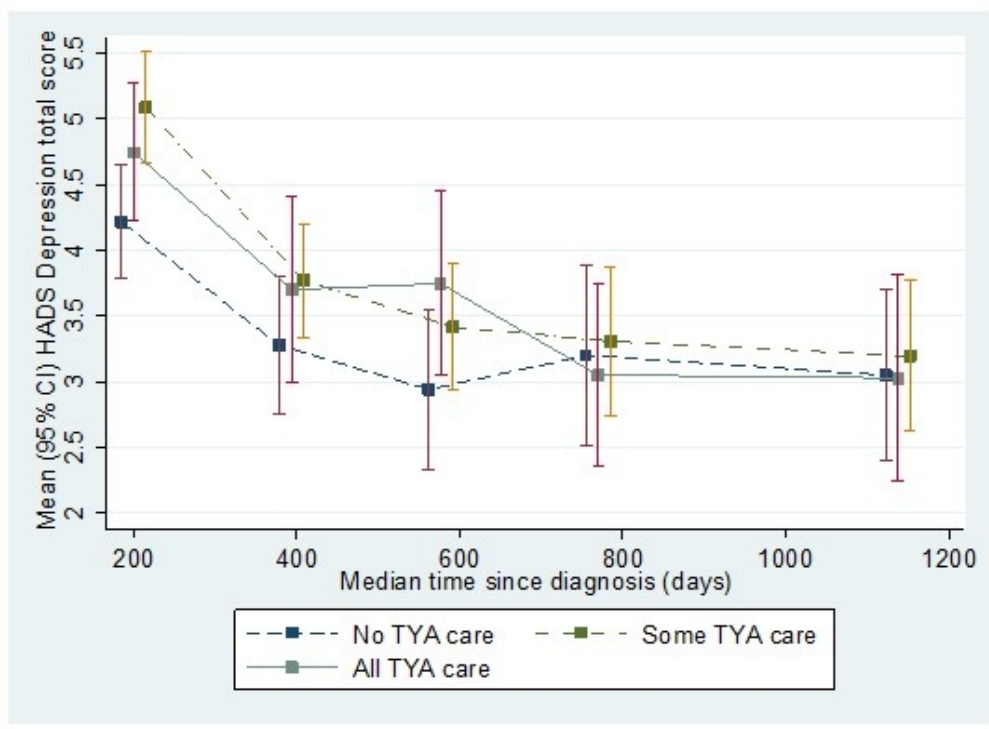


Figure 4: Mean HADS depression scores over time since diagnosis (days) (with 95% confidence intervals)

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Supplemental file

Social support

Sensitivity analysis were conducted because the total social support score had a non-symmetric distribution. A quantile regression with robust standard errors was fitted (Table S1).¹ Results support those from the mixed effects model (main paper, Table 3).

Table S1: Results from quantile regression investigating the relationship between TYA category of care and the Social Support total score

		difference in medians	95% Confidence Interval	P-value
Adjusted model (N=766)				
TYA care category (v NO-TYA-PTC)	SOME-TYA-PTC	0.05	-0.11 to 0.21	P=0.73
	ALL-TYA-PTC	-0.006	-0.16 to 0.15	

Adjusted for time since diagnosis, age at diagnosis, type of cancer, socioeconomic status, severity of cancer, ethnicity, choice about where to receive treatment, long-term condition prior to cancer, days from first symptom to diagnosis, number of general practitioner visits before diagnosis. Missing data due to missing TYA category and missing data in other covariates

Anxiety and depression

Table S2: Frequency of HADS anxiety cases*

	NO-TYA-PTC			SOME-TYA-PTC			ALL-TYA-PTC		
	N	Case	Non case	N	Case	Non case	N	Case	Non case
Wave 1	277	112 (40%)	165 (60%)	312	123 (39%)	189 (61%)	193	79 (41%)	114 (59%)
Wave 2	168	63 (38%)	105 (63%)	201	60 (30%)	141 (70%)	117	40 (34%)	77 (66%)
Wave 3	118	36 (31%)	82 (69%)	154	49 (32%)	105 (68%)	95	33 (35%)	62 (65%)
Wave 4	110	43 (39%)	67 (61%)	110	38 (35%)	72 (65%)	91	34 (37%)	57 (62%)
Wave 5	96	32 (33%)	64 (67%)	107	31 (29%)	76 (71%)	69	18 (26%)	51 (74%)

* Non cases defined as scores 0 to 7 and cases scores 8+

¹ Parente, P.M.D.C. and Santos Silva, J.M.C. (2016), Quantile Regression with Clustered Data, *Journal of Econometric Methods*, 5(1), pp. 1-15

Table S3: Results from multilevel logistic regression model investigating the relationship between categories of TYA care received during the first 12 months from diagnosis and the HADS anxiety cases (case vs. non case)

		Odds ratio	95% Confidence Interval	P-value
Adjusted model (N=733)				
TYA care category (v NO-TYA-PTC)	SOME-TYA-PTC	1.12	0.66 to 1.93	0.66
	ALL-TYA-PTC	1.31	0.73 to 2.34	

Adjusted for time since diagnosis, age at diagnosis, type of cancer, socioeconomic status, severity of cancer, ethnicity, choice about where to receive treatment, long-term condition prior to cancer, days from first symptom to diagnosis, number of general practitioner visits before diagnosis. Missing data due to missing TYA category and missing data in other covariates

Table S4: Frequency of HADS depression cases*

	NO-TYA-PTC			SOME-TYA-PTC			ALL-TYA-PTC		
	N	Case	Non case	N	Case	Non case	N	Case	Non case
Wave 1	277	57 (21%)	220 (79%)	312	69 (22%)	243 (78%)	193	46 (24%)	147 (76%)
Wave 2	168	22 (13%)	146 (87%)	201	29 (14%)	172 (86%)	117	19 (16%)	98 (84%)
Wave 3	118	12 (10%)	106 (90%)	154	19 (12%)	135 (88%)	95	16 (17%)	79 (83%)
Wave 4	110	16 (15%)	94 (85%)	110	13 (12%)	97 (88%)	91	10 (11%)	81 (89%)
Wave 5	96	13 (14%)	83 (86%)	107	7 (7%)	100 (93%)	69	9 (13%)	60 (87%)

* Non cases defined as scores 0 to 7 and cases scores 8+

Table S5: Results from multilevel logistic regression model investigating the relationship between categories of TYA care received during the first 12 months from diagnosis and the HADS depression cases (case vs non case).

		Odds ratio	95% Confidence Interval	P-value
Adjusted model (N=733)				
TYA care category (v NO-TYA-PTC)	SOME-TYA-PTC	1.19	0.63 to 2.25	0.43
	ALL-TYA-PTC	1.48	0.79 to 3.18	

Adjusted for time since diagnosis, age at diagnosis, type of cancer, socioeconomic status, severity of cancer, ethnicity, choice about where to receive treatment, long-term condition prior to cancer, days from first symptom to diagnosis, number of general practitioner visits before diagnosis. Missing data due to missing TYA category and missing data in other covariates

Health status

Sensitivity analysis were conducted because the utility score had a non-symmetric distribution. A quantile regression with robust standard errors was fitted (Table S6)¹. Adjusted estimates were smaller, and differences less significant than in the previous model (main paper Table 3).

Table S6: Results from quantile regression investigating the relationship between TYA category of care and the EQ5D utility score

		Difference in median	95% Confidence Interval	P-value
Adjusted model (N=733)				
TYA care category (v NO-TYA-PTC)	SOME-TYA-PTC	-0.042	-0.080 to -0.005	0.06
	ALL-TYA-PTC	-0.007	-0.048 to 0.034	

Adjusted for time since diagnosis, age at diagnosis, type of cancer, socioeconomic status, severity of cancer, ethnicity, choice about where to receive treatment, long-term condition prior to cancer, days from first symptom to diagnosis, number of general practitioner visits before diagnosis. Missing data due to missing TYA category and missing data in other covariates