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TITLE PAGE

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Title:

Cancer Patient Experience in the Teenage Young Adult Population: Key issues and trends over time. An analysis of the national UK National Cancer Patient Experience Surveys 2010 – 2014.

Human Subjects approval/Protocol Information

The study used anonymous publicly available data from four years of patient experience surveys accessed via the UK Data archive (UKDA), UKDA study numbers 6742, 7134, 7400, 7562.

Abstract

Improving outcomes for teenagers and young adults (TYA) with cancer is a key element of the national cancer strategy in England. Recognition of the unique needs of this group has led to the development of recommendations for specific models of care and delivery of this care through the provision of dedicated clinical units in principal treatment centres across the UK. The aim of this study was to understand the current cancer patient experience for this patient group. We aimed to determine whether treatment experience is influenced by place of treatment and whether it has changed over time using patient reported data from national cancer patient experience surveys. This study highlights that a prolonged pathway to diagnosis remains an issue for the TYA group and identifies areas on which quality improvement measures for TYA services should focus, including communication and involvement of the patient in treatment decisions. Positive experiences for the TYA group such as involvement in research were also highlighted. Treatment within a TYA principal treatment centre (PTC)was associated with positive patient perception in a number of key areas highlighting the need for future studies to fully elucidate the impact of the full range of TYA services now available in the UK on both patient experience and outcome.

Background

Survival trends in teenagers and young adults with cancer are improving but the quality of age appropriate care and patient experience are largely unknown(O'Hara et al, 2015). The 2005 National Institute of Clinical Excellence (NICE) guidance on improving outcomes in paediatric and adolescent cancer patients made key recommendations about provision of cancer care to this age group(NICE, 2005). Key recommendations were delivery of care within a multi-disciplinary framework supported by a range of defined specialist staff including a key worker for each young person with cancer and emphasis on the need for age appropriate facilities.

The needs of young people with cancer are complex and stretch beyond a requirement for state of the art medical care alone. Health related quality of life is significantly impaired in young adults with cancer and high rates of psychological morbidities are reported ((Quinten et al, 2015; Muffly et al, 2016). The potential impact of a cancer diagnosis and treatment on education, employment, income, psychosocial development, fertility and late effects of treatment must all be considered, addressed and minimised.

The publication of the NHS England service specification for TYA cancer has defined commissioning standards for service delivery and peer review against national TYA Cancer Measures to enable independent evaluation of the quality of care given (NHS Standard Contract for Cancer: Teenagers and Young Adults; NHS Manual for Cancer Services Teenage and Young Adult Measures). Together, these standards define specific recommendations concerning network governance overseen by Teenage and Young Adult Cancer Network Co-ordinating groups (TYACN), the configuration of dedicated TYA principal treatment centres (PTCs) and their associated TYA designated hospitals closer to the patient's primary residence as well as the importance of consideration of the holistic needs of every patient in a TYA multidisciplinary team (MDT) meeting, irrespective of place of care. The need to enter TYA patients where possible on to clinical trials and support for regional and national cancer data collection is also acknowledged. Practical support for these measures is set out in a 'blueprint of care' published by TYAC. (A Blueprint of Care for Teenagers and Young Adults with Cancer, 2012). In addition to these initiatives and service standards, there also exists a UK clinical reference group (CRG) for chidlren and young people with cancer whose remit is partly to ensure the adequate delivery of these standards which are also integral to the latest Cancer Strategy for England (2015).

Over the last decade a number of Teenage Cancer Trust supported TYA units have opened around the United Kingdom (23 in England as of May 2016) linked to 13 principal treatment centres (PTCs) for the provision of care for patients aged 13 – 24 years. A PTC offers both dedicated inpatient and outpatient facilities and medical/nursing staff with TYA expertise for patients aged 13 – 24 years. Patients aged <18 with a diagnosis of cancer are usually treated within the PTC whereas those aged 19 – 24 should be offered the choice of PTC directed treatment or treatment within a local designated hospital with TYA specific support accessed via the TYA network co-ordinated by the PTC. All TYA patients regionally are reviewed at a TYA specific multi-disciplinary meeting (MDaT) focused on ensuring the wider TYA needs (e.g. psychosocial and educational) of this age group are discussed and supported. Further refinements to this hub and spoke model within adult services (perhaps based on the shared care model used in paediatric cancer services in England) are likely to be necessary in the future to enable seamless delivery of care to young adult patients irrespective of whether they choose to receive their treatment within a PTC or designated TYA centre.

In summary the last decade has seen increasing focus on identifying and meeting the needs of young people with cancer through the provision of age appropriate facilities, TYA dedicated professionals and the development of service specifications for quality assurance. This study aims to define the issues at the forefront of the current patient experience in the 'TYA era' in order to inform future developments in TYA cancer care. We also aimed to examine whether there has been a stepwise improvement over time and whether delivery of care in a principal treatment centre affects patient experience.

Study Aims

We aimed to address three key study questions.

1. Are there areas where TYA patients as a group have a significantly better or worse experience in comparison to older patients?
2. Within the TYA group how does treatment experience differ depending on the type of centre they were treated in (PTC or none PTC)?
3. Within the TYA group has their treatment experience changed over time?

Methods

Data and methods

The national cancer patient experience survey is a commissioned data collection exercise by NHS England which is undertaken by an external survey provider. It comprises a postal survey of all cancer patients aged 16 and over treated as inpatients or day cases in all 153 NHS Trusts in England that provide adult acute cancer services. Separate surveys have been conducted in 2010, 2012, 2013 and 2014. Sample sizes and response rates have remained consistent over time (response rates of 67% in 2010, 68% in 2012, 64% in 2013 and 2014; corresponding to completed questionnaire numbers of 67,713 in 2010, 71793 in 2012, 68,737 in 2013 and 70,141 in 2014). Response rates were lower in the 16-24 year age group compared to older ages in each survey year; response rate between 31%-38% for 16-24 years compared to 64%-69% for 51-65 year olds, who had the highest response rate in all age groups (data from National Cancer Patient Experience Survey National Reports available at www.quality-health.co.uk).

Copies of the National Cancer Patient Experience Survey for each year of the survey are available at https://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey. De-anonymised individual level patient's responses data were provided by Quality Health for each survey year and subsequently underwent additional coding to enable merging of data across the four years of the survey and to group patient responses according to age (TYA group designated as 16 – 24 years). Focussing on the TYA group only responses were then grouped as to whether treatment was delivered in a TYA principal treatment centre (PTC) or other setting. There were 277,017 patient responses in the survey as a whole and 1367 (0.5%) in the TYA group (age 16 – 24). Supplementary table S1 provides details of all the survey questions.

No specific information about treatment at TYA principal treatment centre was available from the survey responses. We defined the TYA PTC group for the purposes of the data analysis as trusts in which a Teenage Cancer Trust TYA facility linked to a PTC had been made available in the year preceding the survey. It is acknowledged that some patients may have been treated in other clinical areas within the trust rather than within the dedicated TYA inpatient/outpatient service so the proportion of TYA patients treated within the PTC itself (39%) may have been over estimated.

Patient responses to the survey questions were categorical and we assess the percentage of respondents in each category per question by key indicators (TYA vs none TYA, PTC vs none PTC and 2010 vs 2014) to enable us to address each of the three key aims of the paper. In total there were 79 different question asked across all survey years. In order to avoid issues due to multiple testing, and reliance upon p-values only, and as we were interested in looking at a range of issues regarding cancer care and not one specific outcome, we compared responses across categories for each question by the three key indicators and identified questions where there was a 5% or more difference in the proportion of respondents in any response. Although this is still an arbitrary threshold to identify differences we felt this would reflect areas where the responses differed substantially by the key indicators and further analysis could be undertaken. The response categories to these questions were then dichotomised the reflect either a positive or negative experience for each question and exclude responses categories that were that were not applicable for that outcome. For example for the question “Q8. Beforehand, did a member of staff explain what would be done during the test procedure(s)?”, the response categories were: 1) yes, completely, 2) Yes to some extent 3) no but would have liked explanation, 4) did not need explanation 5) Don’t know and 6) not answered. For this question we defined the (negative?) outcome “Procedure not fully explained” which included responses 2) and 3) while the responses 1) and 4) were combined as the comparison group and responses 5) and 6) were excluded from this analysis. Therefore the denominator for each question varies. The response categories used as the outcome for each analysis are shown in tables 2, 3 and 4. These questions were then used in unadjusted and adjusted logistic regression analyses to assess differences in outcomes also adjusting for patient case-mix. The adjusted model included sex, ethnicity, diagnostic group, survey year and type of treatment centre (PTC or not, only included in the models for the TYA only age group).

Results

Dichotomised question responses and logistic regression results (adjusting for potential confounding factors) for the three study questions are summarised in table 2 – 4. Results are summarised below considering the broad areas of time to diagnosis; communication; information provision; confidence and trust in medical staff; patient perception of the respect and dignity with which they were treated and emotional support given; patient family involvement; outpatient care (including interaction with primary care); research; clinical nurse specialist (CNS) interaction; and patient perception of medical care standards.

Pathway to diagnosis

This study validates prior observations that TYA patients are more likely to have a prolonged pathway to diagnosis. The TYA cohort in this study were significantly more likely than the none TYA cohort to have three or more pre referral consultations and as a group felt that they should have been seen much sooner (Table 2). The TYA cohort was more likely to wait more than 12 months from first symptoms to secondary care appointment and their perception was that their health got worse as a result (Table 2). The TYA group were more likely to be seen in a hospital the same or next day which is likely to reflect a higher proportion of aggressive cancers requiring immediate treatment in this group e.g. acute leukaemia. (Table 2) The observation that a negative impact on health whilst waiting for diagnosis was more likely in those treated in a PTC may reflect the caseload referred on to the PTC which acts as the specialist referral centre for complex cases. However it is not possible to comment on this further with the information available other than to state that the caseload is different between PTC and none PTC centres e.g. higher incidence of sarcomas and CNS tumours treated in a PTC (table 1). When 2010 and 2014 survey results were compared patients were more likely to respond that they should have been seen a lot sooner in 2014 than in 2010 (Table 4). Whether this reflects increasing pressure on diagnostic services or a change in patient perception cannot be determined.

Communication and information provision

Excellent communication from all members of the multi-disciplinary team combined with accurate verbal and written information provision is key to high quality cancer care. Study results indicated that this is an area which could be improved upon when dealing with TYA patients as this group were more likely to feel that results and procedures were not explained to them as fully as they desired (Table 2). Positively the TYA group were more likely to have side effects explained to them (Table 2) suggesting that clinical teams are mindful of the burden of late effects on this age group post cancer treatment and more likely to be provided with information on financial help most relevant to this age group where the potential for impact on career decisions and future earning potential is high. When the surveys conducted in 2010 and 2014 were compared TYA patients were more likely to be provided with written information on tests and treatment side effects that they could understand in the later survey (Table 4) which may reflect a positive impact of TYA focussed teams sensitive to the information needs of this patient group in clinical care. Within the PTC treatment group patients were less likely to say that they had issues with understanding of the answers to questions provided by medical staff (Table 3).

Confidence and trust in medical staff

The TYA cohort were more likely to allocate a negative response for questions around trust in the doctors treating them and to feel as if they were not involved enough in treatment decisions compared to older patients (Table 2). More positive responses were reported by patients treated in the PTC (Table 3) and in those treated in 2014 compared to 2010 (Table 4)

Treatment with respect and dignity, emotional support and family involvement

Treatment with respect and dignity is a core requirement of adequate medical care. The TYA group were more likely than the older age group to raise issues such as medical staff talking about them as if they were not there and be concerned that they had deliberately had information withheld from them (Table 3). Patients treated within a PTC were less likely to raise concerns about nurse staff talking about them as if they were not there (Table 3), suggesting that age appropriate carers are more aware of the need to involve patients of all ages in information provision and treatment. Patients treated within a PTC also responded more positively to a question concerning how able they felt to discuss worries and fears (Table 3). Positively the TYA group were more likely to be told to bring a family member or friend to treatment reviews than older patients and no concerns were raised about the opportunities for families to talk to medical staff (Table 3)

Outpatient Care

Questions in the survey concerning outpatient appointments and interaction with primary care suggested room for improvement in the interaction between primary and hospital based care. TYA patients were more likely to raise concerns about support in primary care (Table 2) (improved in 2014 versus 2010 (Table 4), information provision from the hospital to primary care and the ability of multiple professionals to work together in their treatment delivery (Table 2). This may reflect the different expectations of the TYA group rather than a difference in these aspects of care for the TYA group per se but nevertheless highlights the emphasis that TYA patients place on the communication between health professionals to ensure seamless and consistent delivery of quality care to a vulnerable group. Patients treated in the PTC were less likely to feel that their appointments were too short (Table 3).

Medical care standards (patient perception)

TYA patients were more likely to raise waiting times in outpatients as an issue and more likely to suggest that sometimes the doctors treating them could have better knowledge compared to older patients (Table 2). However perception of overall quality of care was not significantly different between any of the groups compared.

Research

The TYA group had a very positive experience of research. They were more likely to be provided with information on cancer research, to discuss it and to take part (Table 2). This is encouraging as increasing trial recruitment in TYA patients is one strategy proposed to improve outcomes as recruitment still lags behind that in children aged 0-14 (Fern et al, 2014).

Clinical Nurse Specialist (CNS) interaction

Cancer specific clinical nurse specialists play a key role in providing information about diagnosis, treatment plan and side effects as well as acting as a first point of contact and as an emotional support. There were no significant differences in access to a CNS for TYA patients compared to the older group which was a positive finding and the likelihood of not being given a CNS was lower in 2014 compared to 2010 (Table 4).

Conclusions

This is the largest study of the experience of care of young people with cancer. The cumulative data from all four years of the national patient experience survey confirms that of previous studies which have highlighted that TYA patients consistently report a poorer experience of cancer care across the majority of domains than patients aged 25 years and over (El Turabi et al, 2013; Lyratzopoulos G. et al, 2012). One of the key findings is that TYA patients are more likely to have multiple medical consultations prior to referral and diagnosis. This is likely to lead to a more negative experience of ongoing cancer care as published work has linked numbers of pre-referral consultations to subsequent patient experience and in our study patients linked longer time to diagnosis with negative impact on health (Mendonca et al, 2016). Education and training of the public and primary care providers and young people themselves is recommended to reduce the time taken for cancer to be considered as a possible diagnosis in young people based on the findings of this and other studies (Dommett et al, 2013; Fern et al, 2013; Lyratzopoulos et al, 2012). The TYA group overall across the four years of the survey highlighted a number of areas of unmet needs in addition to the requirement for more prompt diagnosis. These included better communication including explanations of test procedures and results, more involvement in treatment decisions and better communication between health professionals and primary care. To some extent these issues are addressed in the service specification for young people with cancer but improvement in only some of these areas over time has been seen as exemplified by the 2010/2014 survey comparison. Of concern, the 2014 survey results suggest that there has been no improvement in patient perception that they should have been diagnosed sooner although the authors acknowledge that this reflects patient perception rather than a medical assessment of referral times. Services, networks and commissioners should focus on ensuring that appropriate TYA pathways are in place and developing metrics to assess compliance.

This is the first study to have assessed the impact of place of care on TYA patient experience. Patients treated within a PTC reported a significantly better experience of care compared to those treated in other hospitals in almost all the domains in which a difference was observed. PTC patients were more likely to be provided with information on issues of key importance to them such as financial help and to respond positively to questions concerning understanding of responses to questions and trust in doctors treating them. The limitations surrounding the definition of a PTC discussed below limit the significance of this finding but provide a useful platform on which to design more detailed studies.

Limitations

The main limitation of our analysis is the issue of multiple testing, many outcomes were considered and several comparisons between groups were made therefore some differences in outcome may be statistically significant through chance alone. Rather than focus on p-values to assess statistical significance we present the percentage of respondents for each outcome by the key variables of interest and focus on the magnitude and direction of difference between the groups. We selected questions where there was more than a 5% difference between groups and although this is an arbitrary value we feel this reflects a substantial difference between groups to include in further modelling.

Secondly, the responses to the questions for the logistic regression analysis were dichotomised resulting in loss of information where several groups were combined, particularly for responses with ordered categories. Overall the TYA population only represent 0.5% of all survey response and while this percentage is small we have shown significant variation in experience across a range of domains in this age group compared to older ages. It is acknowledged that some difference between the TYA age group and the older age group will exist as a function of differing perceptions of care due to age specific differences in outlook rather than on differences in care per se.

Finally, the impact of age appropriate services and TYA specific professionals cannot be fully elucidated by this study in view of the limitations surrounding the definition of a PTC. Additionally the impact of TYA services cannot be simply assessed by determining which hospital a patient had their treatment in. Appropriate community support services and input from a tertiary treatment hub (via a TYA specific Multi-disciplinary team meeting) to other TYA nominated (none PTC) hospitals represent examples of care models likely to have a significant impact on patient experience but not accounted for in this study. A detailed, prospective assessment of the impact of care delivery within TYA designated pathways is currently in progress as a key element of the Brightlight Study

Summary

This study demonstrates crucial insights into the experience of cancer care in TYA patients in England. For the first time, we have demonstrated a benefit to the significant changes in delivery of care that have taken place over the last decade, with a number of domains improving over time and a more favourable experience of care reported by those patients treated in TYA PTCs. However, these data also highlight the need for ongoing improvement in care and consideration of the holistic needs of this particular patient group, given that the experience of care reported by TYA patients remains generally poorer to that of patients aged 25 years or older. These data should inform TYA clinicians, networks and policy makers as TYA cancer services are reviewed and developed further. Areas of particularly poor experience could be addressed in future service reconfiguration and usefully incorporated into metrics used to prospectively measure the impact of future service change.

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Conflicts of Interest

Sasha Daly and Caroline Brocklehurst are employed by Teenage Cancer Trust.

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