Specialist cancer services for teenagers and young adults in England: BRIGHTLIGHT research programme

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Scientific summary

The BRIGHTLIGHT research programme

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Scientific summary

Teenagers and young adults who are aged 13–24 years at the time of cancer diagnosis are considered to have poorer cancer outcomes than children and older adults. This led to the publication of guidance by the National Institute for Health and Care Excellence (NICE) in 2005 [NICE. *Guidance on Cancer Services: Improving Outcomes in Children and Young People With Cancer*. 2005. URL: www.nice.org.uk/guidance/csg7/resources/improving-outcomes-in-children-and-young-people-with-cancer-update-773378893 (accessed 28 September 2021)], which recommended that services be specifically provided for young people aged 16–24 years. This guidance was based on limited evidence, and the recommendation that 'age-appropriate' care should be provided by 13 teenage and young adult (TYA) principal treatment centres (TYA-PTCs) across England was supported by professional consensus. All young people aged 16–18 years were to be treated in these TYA-PTCs. Those aged 19–24 years were to be given the choice of whether to be treated in the TYA-PTC or an adult cancer unit closer to home. These hospitals, designated as providing some specialist care, were linked to the TYA-PTC to allow review of young people's care in the PTC-based TYA multidisciplinary team (MDT) meeting, creating networks of care.

The aim of this programme of research was to evaluate the provision of TYA cancer services. Delivery of TYA services in some areas of the country was already well established by the time of the NICE guidance, but was underdeveloped in other areas. There was also variation in how the recommendations were being implemented and, therefore, the evaluation adopted a multiple-methods design that focused on three key aspects of the service: the environment in which care was delivered, the workforce delivering care (health-care professionals), and the people receiving care (young people and their caregivers). Additionally, using data collected through the various studies, a detailed health economic assessment has been made of the costs for young people/caregivers and for the NHS.

Study 1: defining the competencies of health-care professionals caring for teenagers and young adults with cancer

Objective

- The objective was to define the competencies of health-care professionals caring for teenagers and young adults with cancer.

Methods

We conducted an international e-Delphi survey. Our first-round survey used data collected during the feasibility studies underpinning the programme of research. This contained 87 items scored on a 9-point scale ranging from not important to extremely important. Experts were defined as any member of a MDT who had been working with teenagers and young adults with cancer for $\geq$ 12 months. Participants were identified from journal publications, and professional organisations were asked to circulate information. Professionals registered to participate and were sent an online link to the survey. A second-round survey contained 15 items identified in open-ended responses as being important areas of competence.

Results

A total of 179 professionals registered as experts of whom 158 (88%) completed round 1 and 136 out of these 158 (86%) completed round 2. The majority of these professionals were nurses or medical doctors from Europe and North America. Consensus was reached for all 87 items in round 1, with highest consensus on having excellent clinical skills, listening to young people's concerns, being able to communicate about difficult issues and having key attitudes (e.g. being passionate about working with young people with cancer and being committed to caring for them). The highest consensus in round 2 was being able to discuss sensitive subjects; know about current therapies; know normal TYA physical and psychological development; know about the impact of cancer on psychological development; know about the side effects of treatment and how this differs from children and older adults; and know about fertility preservation. There were differences in the levels of agreement between professional groups for certain items. For example, there was more agreement among nurses that key competencies involved providing holistic care, restoring normality and facilitating communication, whereas more medical doctors agreed that they should be able to communicate about cancer and have knowledge of current therapies and availability of clinical trials.

Conclusions

Identifying the competencies required to care for young people with cancer can help inform training programmes specific to TYA cancer care.

Study 2: quantifying specialist care

Objective

- The objective was to develop a metric to objectively measure the amount of specialist TYA cancer care received.

The term ‘specialist’ in this report refers to care delivered in the TYA-PTC.

Methods and results

The metric to quantify specialist care was developed from Hospital Episode Statistics (HES) admitted patient care (APC) data. NHS trusts containing a TYA-PTC were defined and the hospital code was identified from NHS Digital records. For all the patients in the cohort study (i.e. study 4), every APC spell was assigned to either be specialist TYA-PTC care (based on the trust code) or care elsewhere. A proportion of TYA-PTC care was then calculated for each member of the cohort at 6 and 12 months after diagnosis. Care was therefore categorised according to the proportion of specialist care received: ALL, SOME or NONE.

Conclusions

The categories of care are the exposure variable for studies 4–6.

Study 3: understanding the culture of care

Objective

- The objective was to understand the culture of TYA cancer care.

Methods

Data were collected through a multisite case study. Four TYA-PTCs were selected based on work undertaken in the pre-programme feasibility work. Qualitative methods were used to collect data from the TYA-PTC as well as the non-specialist cancer units that were linked to the PTC. This included focused observation, shadowing and semistructured interviews with 29 young people and 41 health-care professionals from 24 NHS hospitals. First, sections of data were analysed and compared with literature to define age-appropriate care. Second, interview transcripts and field notes were analysed thematically to identify themes between, within and across the four cases – deconstructing and reconstructing the components of the culture of care that emerged, thereby enabling synthesis and contextualisation of data.

Results

A simple definition of age-appropriate care could not be made; rather, a conceptual model was identified, comprising seven core interlinked components. The thematic analysis showed that the context of care was dependent on the impact of the physical environment on young people's experiences of socialising and accessing peer support. There were key features of the culture that were clear and visible, and underpinning these were three values at the core of delivering young person-centred care: recognising individuality, empowering young people and promoting normality for young people. For a culture of care to develop that embraced and promoted these core values, several prerequisites were required: health-care professional competence, a concentrated group of young people of reasonable size, effective leadership and 'buy-in' from all health-care professionals.

Conclusions

The importance of effective communication, leadership and multidisciplinary teamworking was evident. This should be recognised and prioritised when developing and evaluating interventions that contribute to the delivery of care to this unique patient group.

Study 4: identifying the patient-reported and clinical outcomes associated with specialist teenage and young adult cancer care

Objective

- The objective was to identify the patient-reported and clinical outcomes associated with specialist TYA cancer care.

Methods

We established a cohort of 1114 young people who were newly diagnosed with cancer between July 2012 and December 2014. Young people were aged 13–24 years at the time of diagnosis, and the only exclusion criteria were receiving a custodial sentence, mental incapacity or not anticipated to be alive at the first point of data collection. Data were collected at the first time point (i.e. 5–7 months after diagnosis) through the BRIGHTLIGHT survey, which was administered through face-to-face interview. The survey contained five validated questionnaires and 169 experience questions. Further data collection occurred at 12, 18, 24 and 36 months after diagnosis through an online version of the survey or telephone interview. Clinical data were also obtained from young people's medical records and from the UK cancer registry. Analysis used random-effects models adjusted for confounding variables and sought relationships to three levels of specialist care experienced (cf. study 2): NONE-TYA-PTC, SOME-TYA-PTC and ALL-TYA-PTC.

Results

The primary end point, quality of life (QoL), differed according to all categories of care. At the first time point, QoL was highest in the NONE-TYA-PTC group, followed by the ALL-TYA-PTC group, and was lowest in the SOME-TYA-PTC group. In all groups, QoL improved over time, but the rate of improvement was greater in the ALL-TYA-PTC and SOME-TYA-PTC groups. A similar ordering of advantage for NONE versus ALL versus SOME was observed for survival, but this was not significant. Differences were small for other outcomes, including social support, health perception, and anxiety and depression. Health utility measured by the EuroQol-5 Dimensions (EQ-5D) favoured the NONE group. There were no demographic or disease factors that helped explain these results after adjusted analyses.

Conclusions

The SOME-TYA-PTC group had unexplained lower QoL and survival than the other groups. It is not known whether or not these differences will persist in specialist TYA services that have been developed and evolved in the period since the cohort was recruited. No clear advantage for specialist TYA care as measured using this exposure variable was evident from the outcomes selected for this study.

Study 5: determining if specialist teenage and young adult services support caregivers' information and support needs

Objective

- The objective was to determine whether or not specialist TYA cancer services support the needs of caregivers of teenagers and young adults with cancer.

Methods

A paper questionnaire measuring information and support needs was developed based on existing literature (i.e. the BRIGHTLIGHT Carer Questionnaire). Twenty-two items were used to describe five domains: support caregivers received, satisfaction with support, information provided, opportunities to make decisions about treatment, and services provided for caregivers. Caregiver data were linked to young person data through a unique study code so comparisons could be made between the three levels of care: NONE-TYA-PTC, SOME-TYA-PTC and ALL-TYA-PTC.

Results

Caregivers of those in ALL-TYA-PTC care had greater satisfaction with support. Where care was delivered in SOME-TYA-PTC care, caregivers received the most amount of information; however, they had fewer opportunities to make decisions. Finally, satisfaction in services provided specifically for caregivers was reported mostly by caregivers who had ALL-TYA-PTC or SOME-TYA-PTC care.

Conclusions

Caregivers who had no contact with a TYA-PTC had the most unmet needs.

Study 6: calculating the cost of specialist teenage and young adult cancer care

Objective

- The objective was to calculate the out-of-pocket costs and cost to the NHS of specialist TYA cancer care.

Methods

Out-of-pocket expenses data were collected from the cohort (study 4) using a Cost of Care Questionnaire at the first point of data collection, reporting costs incurred through a cancer diagnosis from diagnosis to the point of questionnaire completion. During the following 3–6 months, the cohort were asked to complete a cost record recording the same information on a weekly basis. NHS and patient travel costs were calculated from HES data. Quality-adjusted life-years (QALYs) were calculated using the EQ-5D.

Results

Hospital costs were available for 1044 young people and out-of-pocket expenses data were available for 733. These data showed that hospital costs and travel costs were highest for those in the SOME-TYA-PTC group and lowest in the NONE-TYA-PTC group. Out-of-pocket expenses data showed that young people in ALL-TYA-PTC care incurred the highest cost and those in NONE-TYA-PTC care incurred the lowest cost. Finally, although QALYs were highest in young people receiving NONE-TYA-PTC care and lowest for those in SOME-TYA-PTC care, this was not significant.

Conclusions

Mean adjusted NHS costs were higher among young people who had access to the TYA than among those who received none of their care at a TYA-PTC. These costs were around £16,000 higher in the first year after diagnosis for those who had some of their care at a TYA-PTC and around £5000 higher for those who had all of their care at a TYA-PTC.

Conclusion

It is evident from this study that young people in England experience good cancer care irrespective of where they are treated. This is expected by young people, caregivers and health-care professionals. Specialist TYA care also provides an environment that is valued by young people, opportunities for peer interaction and support from a range of experienced support staff who can assist with non-medical aspects of care (e.g. reintegration back into life after cancer treatment). There is national variation in how this additional support is delivered though our metric that defines specialist care, which, while robust and objectively created, was based on the premise that all services are equal. This may help explain, in part, why our quantitative evaluation of cancer services for young people provided divergent conclusions from the qualitative data gathered in study 3. There is no single answer to the original question ‘Do specialist cancer services for TYA [teenagers and young adults] add value?’, but it is not clear that there is improved QoL or survival associated with greater exposure to specialist care as measured in this study.

What has become evident through the duration of the study is this is a far more complex question to answer than we had anticipated. This was highlighted in study 3 in which a simple definition of age-appropriate care could not be developed; rather, a conceptual model was ultimately proposed. Study 3 also highlighted that culture needed time to evolve and become embedded as standard care within a hospital setting. Study 4 was conducted during a period where approximately 50% of TYA-PTCs had implemented the 2005 NICE guidance. Many changes to services have been implemented based on clinical need rather than evidence or guidance. These processes, in addition to time, have potentially enabled the culture of TYA care to become embedded nationally, not just locally. Based on these observations, we suggest that, if study 4 were conducted now (i.e. in 2021), then young people’s QoL would be similar to the levels of QoL in 2012–14 if they have input from the TYA-PTC (all and some group), and the survival rate might be greater. Furthermore, additional work should be undertaken that would better explain ‘specialist’ care that uses the model of age-appropriate care to develop a more precise metric of specialist care. Analysis of cohort data could therefore be undertaken using methods that do not assume a linear cause and effect.

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