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Mapping Adolescent Cancer Services: How Do Young People, Their Families, and Staff Describe Specialized Cancer Care in England?

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Introduction

Specialized cancer services for adolescents and young adults (AYAs) are being developed in a number of countries to address the particular needs of this patient group and their families. Previous research has demonstrated that patients in this transitional age range have different characteristics, concerns, and needs from child and adult patient groups¹. For these reasons, developmentally appropriate specialist models of AYA cancer care have been advocated, with a primary aim of improving health outcomes, quality of life and patient experience^{2,3,4}; however, the evidence-base to inform service design and delivery remains underdeveloped. Our focus

here is to contribute to the understanding of AYA cancer care by identifying the main components of AYA cancer care in England. These components were extracted from interview responses of young people receiving specialized cancer services, their family members, and health and social care staff. The interviews took place as part of an exercise to Map Teenage and Young Adult Cancer Services in England: The BRIGHTLIGHT Directory of Care (NHS Ethics Reference: 12/EM/0316). It is hoped that the identification of these components can assist clinical teams when designing or reconfiguring services for AYA with cancer.

Background

A diagnosis of cancer can have a particular impact when it takes place during adolescence and young adulthood, as it disrupts development and interferes with psychosocial processes that are instrumental in the construction of identity, the establishment of career and family goals, and the formation of social relationships and emotional ties⁵. The pattern of cancer types in AYAs is different from children or older adults and they have a different response to treatment⁶. Previous research has documented issues with treatment adherence and therapy tolerance in AYAs, possibly contributing to the lower survival rates seen in some cancer types when compared to other patient age groups^{7,8,9}. Generally in this population, there are fewer studies, and thus there remains a weak evidence-base to inform care and service delivery. Important areas of research for AYA include relevance and impact of time to diagnosis and impact on survival¹⁰, place of care¹¹ and transition to adult services¹², participation in clinical trials,^{13,14} and survivorship care¹⁵.

Despite this lack of evidence, there is an agreed international goal to provide access to quality care¹⁶ and to develop guidelines for AYA cancer care²⁰, with the aim to promote and inform multidisciplinary specialized teams of professionals who can deliver medical care within integrated service programs that provide support relevant to this patient population, such as education, employment, financial and family needs, fertility and sexuality, body image, and social relationships^{17,18}. Additionally, professionals in the field are strengthening collaborations and engaging with researchers with diverse skills to address unanswered questions^{19,20}. Approaches to care, also, need to be flexible and individualized to allow various levels of independence and participation in decision-making, as each young person will present a particular set of priorities and preferences⁷.

The development of AYA cancer services is well underway in a number of countries. The United Kingdom (UK) was one of the first countries to describe a philosophy of AYA cancer care, distinguished as different from both child and adult focused care, with the establishment of the first Teenage Cancer Trust specialized center in London in the 1990s^{19,21}. Since that time, through high profile lobbying, Teenage Cancer Trust has ensured that access to services has been increased for young people through the development of a further 26 age-specific units²². In the United States (US), the Children's Oncology Group, funded by the National Cancer Institute, created the Adolescent and Young Adult Committee in 2000⁵. This committee sought to improve treatment adherence, reduce the number of side-effects generated by treatments, to improve continuity of care and long-term follow-up, and research obstacles to participation in clinical trials¹⁷. There have been a series of AYA programs developed across the USA, for

instance at the University of Texas M.D. Anderson Cancer Center, the Dana-Farber Cancer Institute, and the Oregon Health Science University Knight Cancer Institute¹⁷. The UCLA Daltrey/Townshend Teen and Young Adult Cancer Program, modelled after Teenage Cancer Trust in the UK, will create the first AYA unit in the United States²³. In Canada, the Canadian Partnership against Cancer and a consortium of pediatric cancer centers created a national task force in 2008 to guarantee all AYAs receive adequate cancer care and promote research on treatment outcomes and quality of life^{17,24,25}. The onTrac@PeterMac program was established in 2004 in Victoria, Australia to provide care to cancer patients age 15 to 25¹⁷ and subsequently a National Service Delivery Framework was published to direct the development of services in each State^{26,27}. In mainland Europe, there are examples of AYA service developments at particular institutions, for example an AYA inpatient room and common areas for patients age 14-24 at the Centro di Riferimento Oncologico, Aviano, Italy; inpatient and outpatient units for 17-35 year olds at the Radboud University Nijmegen Medical Center, The Netherlands; and in Denmark, a youth ward for patients 15-21 years of age at the Aarhus University Hospital²⁸. There are also specialist units in other countries. There is much variation between different cancer services regarding meeting the needs of AYA patients. At one end of the continuum of identified AYA cancer services, young people may be cared for in a designated AYA nursing bay in either an adult or children's hospital, and at the other, in purpose built AYA cancer units with specially trained AYA staff. Outside of this range would be facilities designed for children or older adults, described here as non-specialist centers, where AYA are cared for by non-AYA specialist healthcare professionals. Services are however developing and changing all of the time to reflect current policy and practice, where often policy is directing change, particularly in

the UK National Health Service (NHS) which advocates a more unified national approach when compared to single-institution developments in other health care systems.

In the UK, the National Institute for Health and Care Excellence (NICE) published the *Improving Outcomes Guidance (IOG)* in 2005 and the associated quality standards in 2014, acknowledging AYA as a group distinct from younger children and older adults and highlighting the need for specialized services^{29,30}. The 2005 guidance recommended referral of all cancer patients who are between 13 and 19 years of age to a principal treatment center for their care. Cancer patients who are 19-24 years old should be offered the choice of either receiving care in a principal treatment center or in identified, AYA-enhanced, adult cancer service nearer to their home. There are now 13 principal treatment centers in England, with a remit to deliver tumor site-specific expertise in conjunction with psychosocial support for young people and their families, and to coordinate access to age-appropriate support for young people who elect to receive care outside the principal treatment center.

The 2005 guidance, based on best available evidence and expert opinion, represents a notable contribution to the development of age-specific cancer services. However, a decade after publication, the question still remains whether these specialized services add value to the care provided to young people with cancer. The issue of 'added value' is an important one as without evidence of additional outcome benefit, it is difficult for service providers to make the case for financial investment or reconfiguration of services. Local champions being creative with local solutions might not be enough to sustain services. Even examples like the Canadian

Task Force, who have made six broad recommendations for improved provision of care for this population, that has their unique needs, related to their developmental stage at the core of service delivery³¹, may need to confront the notion of ‘affordability’³². Decisions made by health providers will need to consider cost, effectiveness, equity and feasibility³³. It may be necessary to consider novel customization to address priorities³⁴; priority setting, where services may have to give more weight and consideration to some elements of a service rather than others, those that do in fact ‘add value’.

In an attempt to answer the question of ‘added value’, a National Institute for Health Research (NIHR) funded cohort study called ‘BRIGHTLIGHT’ is being conducted in England. BRIGHTLIGHT will follow a cohort of young people diagnosed with cancer over a three-year period (<http://www.brightlightstudy.com/about-the-study.aspx>). The aims of the study are to identify the most valuable parts of AYA specialist cancer care to evaluate if specialist AYA cancer care affects outcome; to calculate the costs of specialist AYA cancer care; and to identify the opportunities for organizational and clinical change, which may improve services for AYAs with cancer. BRIGHTLIGHT will also explore the “culture of care” through participant and non-participant observation, walking and semi-structured interviews, and analysis of departmental documents of four selected cases (principal treatment centers) and their associated networks of care. The BRIGHTLIGHT case study was preceded by a mapping exercise, which is our focus in this current article.

The *mapping TYA cancer services in England* study was a companion study to BRIGHTLIGHT and it sought in essence to describe *where* AYA cancer care is delivered, *who* delivered it, and *how* it was delivered. The Mapping study had two main goals:

- 1) *To identify the main components of AYA cancer care in England.* To map current services, and to begin to describe the culture of care, seeking out differences as well as similarities, in order to inform an observation and interview guide for the in-depth case studies that would follow.
- 2) *To inform the selection of four sites and their Networks for our following study titled The Culture of TYA Care: BRIGHTLIGHT Case Study (part of the NIHR funded program of work evaluating AYA cancer care in England, RP-PG-1209-10013).* Each principal treatment center and its network of care have unique clinical configurations of care, and function within different socio-geographical contexts. To be fully conversant with this variation in context, and in order to inform an unbiased selection of cases, principal treatment centers were studied to understand types of service delivery.

Study objectives

- To understand the geographical layout of the AYA unit in each principal treatment center;
- To catalogue key weekly events within each principal treatment center as described by health professionals;
- To catalogue key weekly events within each principal treatment center as described by young people;

- To identify other areas within the network of care that deliver care to young people;
- To identify healthcare providers external to the host center, within the network of the principal treatment center who provide care for young people;
- To define the roles of external organizations providing care;
- To understand from a range of perspectives how care was received and described by
 - young people
 - parents and other family members
 - health care professionals

Methods

Design

This was a qualitative study designed to provide an overview of AYA cancer care across England. It used a rapid appraisal approach where data were collected and analyzed in a targeted way within limited timeframes to address specific goals³⁵.

Setting and sample

Specialist AYA care in England is centered in 13 principal treatment centers; each providing cancer site-specific expertise and age-appropriate psychosocial care for young people across a defined geographical region. A convenience sample of young people, and family members in 11 of the principal treatment centers were invited to participate. The age group for this study was 13 to 24 years of age, this upper age limit for services in the UK resulted from discussion of the advisory group charged with implementation of NICE Guidance on cancer services²⁹. Inclusion

criteria included: Young People: In-patients for the duration of the study (3 days); Family members: resident or visited the unit on more than 1 occasion. A purposive sampling technique was used to recruit staff.

The researcher aimed to recruit three young people, three family members, and three staff¹ members in each principal treatment center. The total number recruited was: 21 young people, 15 family members, and 34 staff members.

Data collection

Semi-structured, open-ended interviews were carried out with staff, young people and their family members. The interviews with the young people focused on documenting their experience of care. The researcher asked about their care trajectory, the areas of care, people, and things on the wards they considered helpful and unhelpful, and aspects of their care they thought should be improved. The interviews with family members focused on understanding the ways in which AYA services adapted to fit their needs. Family members were also asked to identify helpful and unhelpful areas and services (for young people and family members) they thought should be improved. Staff were asked about the history of AYA services in their principal treatment center, the challenges to developing these services, and what aspects of their service they consider to be of greatest benefit to young people and their families.

¹ The term 'staff' has been used to describe all the members of the multi-disciplinary team who provided care to AYA in the principal treatment centres. This includes healthcare professionals (medical doctors, nurses and allied health professionals) but also social workers and youth support coordinators.

Relevant documents were collected that provided information about the organizational context of each service, such as: operational policies and standard operating procedures.

The researcher visited 11 principal treatment centers. As the researcher was external to each organization she spent from 1-5 days at each site, familiarized herself with the environment, noting all the areas where AYA received care in order to place the interviews in context. In addition, communal areas in the AYA units such as the kitchens, family rooms, lounge, and recreational rooms used by young people and their families were all visited. The environment is known to assist in supporting positive physical and psychological adjustment³⁶, the researcher therefore needed to be cognizant of 'the environment' at each site visited. Field notes were used to document the context and environment at each site.

Data analysis

Our focus was on the interviews, supplemented with field notes, to explore what was perceived by expert 'insiders' (patients, families, staff) as helpful and less helpful in each setting; to address our two study goals.

Each interview was transcribed verbatim. The purpose was to synthesize large quantities of interview data into a limited set of components that could be used to describe AYA cancer care from the perspective of staff, young people, and family members. When working with the interview data we used an adaptation of the model presented by Levasseur et al. (2010)³⁷, which has been used as an effective technique to define concepts and identify their underlying dimensions.

Qualitative content analysis was used initially at principal treatment center level to describe care from the young person, family, and staff perspective. Content analysis is a research method for making valid inferences from data to their context, to attain a condensed and broad description of the phenomenon, usually to build up a model, conceptual system, conceptual map or categories³⁸. At a later stage in analysis data were compared across principal treatment centers to search for similarities and differences between the different perspectives: drawing on field notes were relevant. These data were summarized in Tables describing each site by one researcher (CVP). A team of five researchers read through a group of randomly selected transcripts from the three groups (FG, SL, LH SP, RT). They met to discuss the recurring themes in the interviews asking questions of the data to explore the nature of age-appropriate care, by constantly asking ‘is this relevant only to AYA?’, ‘What is different and the same with other cancer populations?’. These themes were grouped in the following categories:

- Young people: “You as a person”/Friends/Facilities and things to do/Spaces;
- Family members: “You as a person”/Friends/Facilities and things to do/Spaces;
- Staff: Definition of the staff member’s role/Challenges establishing AYA cancer care delivery/Differences between A and YA models/The art or “philosophy” of AYA cancer care delivery/Environment of care.

The transcripts were then divided evenly among the five researchers and organized in the categories mentioned above. The data were arranged in one master spreadsheet for each group, where each column represented one of these categories. After examining the

spreadsheet, the research team agreed that the data could be used to 'build up a model' describing the key components of AYA cancer care, an exercise that could be useful for clinical teams when designing or refining their services, or where needs might need to be a prioritized when delivering AYA care in a non-specialist center.

Following this presentation decision, one of the researchers (CVP) went through each column and further summarized the content, and performed an extraction of the main elements the interviewees identified as relevant to AYA cancer care. The team of researchers met again to review the process of data synthesis and discuss the selection of components of AYA cancer care.

A list of agreed questions was used to interrogate data collected regarding the service delivered to provide a summary of each site to provide an accurate description of each service to answer each of our study objectives. Data for each of the 11 sites were presented to members of an expert panel. Independently they selected cases for the subsequent in-depth case study research based on the criteria in Table 1.

Ethics

National Health Services (NHS) ethical approval was gained to undertake data collection in all 13 principal treatment centers (REC reference: 12/EM/0316). In accordance with NHS research governance, local Trust Research & Development approval was sought from the 13 principal treatment centers. Although we envisaged that there would be variation among Trusts in terms

of time to approval, we faced some significant procedural and local challenges. Time from first contact with the local site to the start of data collection varied from 7-9 months which meant that we were only able to collect interview data in 11 of the 13 principal treatment centers: all 13 sites were however included in the case selection process.

Results

Study goal one was achieved and we were able to describe the main components of age-appropriate care. Each participant group discussed particular aspects of AYA cancer care. Verbatim phrases were extracted from each interviewee with reference to the care they received or provided (Table 2), to illustrate, refine, and support the identification of these categories directly from the interviewee's conversations. The young people mentioned the value of being able to participate in fun activities with people their own age, while the staff talked about the benefits of having a multidisciplinary team. However, when we further summarized their descriptions of care and organized them into categories (Table 3), we were able to identify areas all three groups considered important, and those that were particularly stressed by different individuals and groups. For example, all three groups mentioned the staff and environment, while young people also talked about activities. One young person commented on the activities saying, "Arts and crafts. I do a lot of that. It takes me away from like being in hospital".

Young people and family members recognized the value of having staff members who were kind, supportive, and listened to them. When asked about the things she liked about the unit, a

young woman replied, “Oh the nurses. I love the nurses! They are lovely. That is one thing I really like about this place, the nurses. They make me feel better when I am down”. Staff also considered this important, but added that AYA staff should also have specialized training, be a part of a multidisciplinary team, and provide holistic care. One staff member described the value of the MDT as, “having a team of people that you are working with, having them as physical presence and having them in the same place. We didn’t have that before. I think that is really, really helpful”. Family members and staff talked about the units being “home away from home”. As one staff member said, “the patients are generally happier because it is a nicer environment [...] We are providing a high level of holistic individualised patient care because we are lucky enough to have this environment”. Another staff member described the unit saying “we have things like computers and telly’s, pool tables, little things like that that they don’t always want to do but they are there as an option and to try to make it as comfortable as possible”. The young people highlighted the importance of having private spaces and different types of rooms or atmospheres to visit on the ward.

Further synthesis of the descriptions of each category allowed us to create the diagram presented in Figure 1. The identified key components of AYA cancer care were: caring and supportive staff, activities designed for AYAs and an environment that feels like home.

Study goal two was achieved and there was consensus on the four sites selected. The sites were selected to represent diversity in geographical coverage, shared management arrangements, patient population, availability of AYA services, distribution of AYA services across different age

groups, size of the service, record of participation in AYA research, and history of the service. At the first site, the principal treatment center is in a large inner-city hospital that serves a dense patient population, within an extensive network of designated trusts and shared care units. The second site serves a wider geographical area, and hosts two combined principal treatment centers in separate cities. The third network spans an even larger geographical region, across five counties, with a well-established AYA team within the principal treatment center and a developed network of care. The fourth site is a much younger service that has only been open for just under two years.

Discussion

This rapid appraisal of principal treatment centers allowed us to identify a range of organizational approaches to the delivery of AYA care. Four sites, representing different ways of providing AYA services, were selected for a future in-depth study. By providing the wider research team with detailed descriptions of each principal treatment center it enabled a decision to be made based on evidence rather than *a priori* judgment. Furthermore, basing selection on key elements reflected in other units or novel to the single unit will ensure the main case study will reflect a range of current AYA cancer care practices in England.

Our exploration of young people, staff, and family members' perception of AYA services indicated that all three groups identified similar areas of AYA cancer care (staff, environment, and activities). Caring and supportive staff were described as staff taking their time to get to know the young person and going the extra mile to provide care. An environment that feels like

home was seen as comfortable and safe, filled with a positive atmosphere, and attempting to be “normal” (not representing a hospital environment). Services for AYA must also include a wide range of age-appropriate activities where young people can interact with other people of their same age and have fun. An important aspect of these activities was the fact that these activities were optional, thus giving young people the power to choose if they would like to take part. This is consistent with previous research on the development of specialized cancer care with AYAs that has found that young people value support services and care environments tailored to their age group^{4,39,40}. In previous work, AYA listed their top three priorities were to have a dedicated unit in place, enabling contact with peers, and provision for partners/parents to live in the unit with them⁴¹. Contrast these priorities with healthcare professionals, where best chance of survival and best quality of life, access to expertise, access to computers/Internet, and age-appropriate equipment were considered of high importance. The need to consult with all stakeholders is a key message here when designing AYA cancer services. The need to consider health service policy, cancer policy, support for healthcare professionals, and be inclusive of young people is a key imperative³⁶.

During our analysis of the interviews we were also able to identify components that were not represented as part of AYA cancer care, such as clinical expertise. Only some of the interviews touched on the importance of having a knowledgeable team. Other research on young people’s perception of AYA cancer care has pointed to a similar situation, where young people identify the place of care, psychological support, the role of peers, their relationship with healthcare professionals, and life after cancer as the main components of their care experience, without

necessarily focusing on the team's clinical expertise⁴. A reason for this could be that it is assumed that the team will have the knowledge and experience required to care for young people, but other areas of specialized care such as a comfortable environment, staff capable of listening and providing individualized care, or recreational activities are not usually part of the services provided to young people, but are highly valued by this group and feature prominently in their interview data. In addition it seems reasonable to assume that if the patients, families or staff perceived a *lack* of clinical expertise this would have indeed featured in their interviews.

At this stage, our description could offer to readers an opportunity to be inclusive of the voice of young people when prioritizing need in service design. In the current absence of data regarding 'added value' of AYA specialist units, and where there are questions about 'affordability and access', 'what is age-appropriate care', and 'how do we make the best use of our environment', our description could support prioritization decisions: where there needs to be a decision between what is essential and what is desirable. A consensus process could then be used to prioritize the key components of AYA cancer care where caring and supportive staff, activities designed for AYAs and an environment that feels like home are all considered in the decision-making process. The initiative to improve services for AYA with cancer is of international concern, but in all countries there will be competing health priorities, and the question of 'added value', might need to be listed as 'most important'. But, until we know the answer to this question, other priorities will need to be considered, and contextualized to different cultural settings: the description here could facilitate this process.

Limitations

In relation to our first goal, this was a discrete, preliminary study, which used a small sample size. Recruitment target for staff was achieved but we struggled to recruit young people and their associated family members. Many of the young people on the wards were in delicate health condition, often dealing with side-effects of treatment such as fatigue and nausea, and did not feel well enough to participate. The participants were only recruited in the designated AYA inpatient units in the principal treatment centers. Their experiences of AYA cancer care may not be representative of the entire population of AYA cancer patients who might receive care in other settings. In order to address these limitations, we have designed our future case study, where we will analyze four of the 13 principal treatment centers, in different care settings and associated local care providers in greater depth. A researcher will collect data over a more prolonged period of time in each unit, approximately three months, thus offering greater flexibility around timings for interviews. This study will allow us refine the main components of care, to identify what age-appropriate care means.

In relation to our second study goal, we were unable to gain access to two of the principal treatment centers and although information about these services in the public domain was accessed, interview data were absent, and may have impacted on site selection. Anecdotally, we were aware that one of these centers was the most embryonic of the principal treatment centers and this may have highlighted some experiences no longer an issue in more established units. The second principal treatment center provides services for one of the most

geographically diverse services in England: other important service variables that influence experience may have impacted on site selection.

Conclusions

We have described here a mapping process that resulted in a description of AYA cancer care and facilitated an un-biased selection of sites to be examined in an in-depth case study of AYA services. This description identifies higher-level components of age-specific care for adolescents and young adults. We will continue to refine and expand it, adding increasing levels of detail regarding the particular approaches and features that constitute age-appropriate cancer services for AYA from our in-depth case study work, due to report at the end of 2016. We offer our work so far for scrutiny and comment, and hope it can serve as a starting point for other practitioners and researchers interested in understanding, developing, or refining the care of young people with cancer, irrespective of the setting in which that care is delivered: specialist or non-specialist. Published evidence to date suggests that the setting in which treatment takes place can have a profound effect on young people, but we perceive that the nature of the optimum care setting has yet to be adequately described. At this stage, our description could offer a way of prioritizing need based on the key components young people consider as being essential for their care. It could enable new and well-established services to assess their service against these key components as quality benchmarks. It could also go some way to address international AYA goals outlined in The International Charter of Rights for Young People with Cancer (<http://www.seventyk.org/about/mission>) to provide a mechanism to advocate and support global change, that may redress the current disparities in care provision.

More broadly there may be aspects of this preliminary work that have relevance for young people's services outside cancer care and may have resonance for those offering cancer services for people at different phases of the lifespan, such as elders, to consider what constitutes 'age-appropriate' care for other patient groups. But importantly for AYA cancer services, our work to describe 'added value' in the context of a range of models of care to be examined in the case studies and the longitudinal study (BRIGHTLIGHT), will inform the international community about the elements of cancer care that has an impact on outcome. Until then, those involved in the design of services will need to consider the range of evidence, from the perspective of all stakeholders, to offer AYA who have unique developmental needs, a quality service.

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