Teenage Cancer Trust, in collaboration with
Coventry University, Leeds Teaching Hospitals
and the Knowledge Transfer Partnership

EVALUATION OF THE TEENAGE AND YOUNG ADULT CANCER SERVICE, LEEDS

COMPREHENSIVE REPORT

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TEENAGE
CANCER
TRUST

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ABBREVIATIONS

CNS	Clinical Nurse Specialist
DoH	Department of Health
IOG	Improving Outcomes Guidance
MDT	Multidisciplinary Team
NCAT	National Cancer Action Team
NCSI	National Cancer Survivorship Initiative
NHS	National Cancer Service
NICE	National Institute for Health and Clinical Excellence
TYA	Teenagers and Young Adults
WHO	World Health Organisation
YP	Young Person
YSC	Youth Support Co-ordinator

EXECUTIVE SUMMARY

BACKGROUND

Every year approximately 2000 young people aged 15-24 in the UK will be diagnosed with cancer (O'Hara & Moran 2012). There is growing recognition that young people in this age group have distinct clinical and psychosocial needs. As such, national models of care and working practices have been developed in NICE (2005) guidelines: *Improving Outcomes in Children and Young People with Cancer.*

At grass-roots level, Teenage Cancer Trust have been instrumental in influencing health care policy for this age group and have financed the building of 25 specialist units throughout the UK. They also fund a number of clinical and TYA expert posts.

EVALUATION AND METHODS

This was the first systematic evaluation to be conducted at any of the specialist units funded by the Teenage Cancer Trust, and its aims were:

- To evaluate the specialist support offered to teenagers and young adults with cancer, and their families and carers.
- To identify examples of 'good practice' in meeting their needs.
- To identify any areas amenable to improvement, and/or any unmet needs.

The evaluation was conducted across the Leeds teenage and young adult cancer service, between May 2011 and April 2013. A mixed-methods approach included participant observation, and 40 multiple perspective interviews with young people, parents, partners, clinical staff and allied health professionals. All participants are reported using pseudonyms. Qualitative content analysis evaluated the findings against needs set out in the 2010 International Charter of Rights for Young People with Cancer (http://cancercharter.org),

KEY FINDINGS

MEETING PATIENT EXPECTATIONS

Various aspects of the service were evaluated to ascertain how and to what extent young people's needs were being met. These included facilities and environment, and also information sharing around medical knowledge, fertility and finishing treatment.

Best Practice

- Young people were happy with the excellent facilities, and daily regimes on the units.
- Information sharing was generally of a high standard, particularly medical information.
- Young people's involvement in clinical trials were above the national average.

Recommendations

- Uniform guidelines to be developed around providing fertility information to young people.
- A comprehensive end of treatment review, and plan to be given to all young people.

THE MULTIDISCIPLINARY PSYCHOSOCIAL SUPPORT TEAM

The multi disciplinary team included, a wide range of clinical staff and allied health professionals:

Best Practice

- The multidisciplinary psychosocial support integrated and generally worked well together.
- Support received by young people and their carers from dedicated CNS's and YSC's was excellent, and helped to alleviate psychological distress and anxiety.

Recommendations

- Information pack to be given out at diagnosis, outlining what the service provides, and the different psychosocial support available from the team.
- To utilise social workers to their fullest potential and capability, that is, beyond the general perception of benefits and employment advisors.
- Review how formal psychosocial screening is carried out throughout the cancer journey.
- Develop formal assessment tool for carers' psychosocial and physical health needs.

SERVICE COHESION AND WORKING PRACTICES

The specialist model of care that has developed for teenagers and young adults, has been forged amidst two existing, but very different ideological ways of working. That is, paediatric health care, and adult health care. This was found to be the main, and ongoing obstacle in transition and the management of young people aged 16-18. The service was also split over two geographical sites, which could create further difficulties.

Best Practice

- Staff were committed to a symbiotic philosophy of medical and psychosocial care.
- Dedicated range of weekly TYA MDT clinical and psychosocial meetings.
- TYA clinical Leads and staff successfully work across paediatric/adult divide to sustain and mediate uninterrupted care for young people aged 16-18.

Recommendations

- Provide a list of desired outcomes for the service in a variety of media, and display visibly.
- Systematic process required to maintain connections, and ensure cohesion between each age aspect of the service.
- Systematic process to provide regular feed-back from clinical and psychosocial meetings to 13-18 and 18-25 ward staff, and others involved in the care of the young person.
- Dedicated lead to organise and mediate transition. For most young people, dependent on their individual circumstances, it would be appropriate to transition from the 13-16 TYA unit to the 18-25 TYA unit first. This would affect a smoother and less abrupt cultural change.

FURTHER RESEARCH

Some aspects of the service have been highlighted that would benefit from more in-depth exploration. These areas include psychological support and the complex needs of TYA's; young people's experiences of fertility issues; and also research into the psychosocial health needs of carers.

Other areas in need of research are the follow-up care service for young people that is provided at Leeds, the late-effects clinics, and young people's experiences of transition to adult services.

Finally, the results of this one regional study also highlights the need for a national evaluation of the benefits of specialist cancer services for TYA's.

Contents

INTRODUCTION

BACKGROUND AND CONTEXT

Every year approximately 2000 teenagers and young adults (TYA) aged 15-24 in the UK will be diagnosed with cancer, and around 300 young people will die from their cancer (O'Hara & Moran 2012). There is growing recognition that young people in this age group have unique needs that are different to those of younger children and older adults (Kelly & Gibson 2008; Lewis & Morgan 2007; Ramphal et al 2011; Smith & Case 2012; Whiteson 2003; 2005). As such, treatment has advanced over the past 10 years in order to fill this gap in provision. In terms of general cancer directives, the Calman-Hine Report (DoH 1995), was instrumental in driving through a psychosocial model of care for cancer patients that not only included clinical treatment, but also acknowledged the wider practical, emotional, psychological and spiritual needs of patients, and their families, and carers. In addition, the Cancer Reform Strategy (2007), directs cancer services to 2020, and includes strategies for the prevention of cancer and early diagnosis; better treatment; living with and beyond cancer; reducing cancer inequalities; choice; stronger commissioning; and, importantly, the delivery of care in age appropriate settings.

More focused initiatives on young people have come from the National Cancer Action Team, who, in conjunction with NICE (2005) guidelines: *Improving Outcomes in Children and Young People with Cancer* (IOG), provided a map to 2013 for Cancer Networks and TYA Services. They encouraged new models of care and working practices, and quality measures for the development of TYA cancer services. The IOG also recommended that young people aged 15-18 be treated in Principal Treatment Centres, whereas those aged 19-24 should be given a choice. In July 2011 the National Cancer Action Team, in line with NICE guidelines, extended the Manual for Cancer Services to include TYA measures that concentrated on clinical and patient outcomes for general and site specific tumours. These measures focused on the arrangements, needs and support particular to young people in their transition from childhood to adulthood.

At grass-roots level, a number of charity organisations have worked together to campaign for the rights of TYA's with cancer. One of the major outcomes of this collective has been the creation of *The International Charter of Rights for Young People with Cancer*. This charter, launched in June 2010, highlights 10 key rights relating to each stage of the cancer journey, and focuses on the unique educational, social, psychological and developmental needs of teenagers and young people:

1. Receive education about cancer and its prevention including early detection.
2. Be taken seriously when seeking medical attention and receive the earliest possible diagnosis and speedy referral for suspected cancer.
3. Have access to suitably qualified multi-disciplinary medical specialists with significant experience in treating cancer in this age group.
4. Information about and reasonable access to clinical trials and treatment that has been clinically trialled with people in their age group.
5. Receive age-appropriate support including, but not limited to, psychosocial, community and palliative support services.
6. Empowerment in making decisions supported by full and detailed explanation of all treatment options and long-term effects of the disease enabling them to actively influence their care.
7. Fertility preservation, as well as information and counselling concerning short-term and long-term effects of cancer and treatment which affect fertility.
8. Have access to specialised treatment and services in age-appropriate facilities alongside their peers.
9. Financial and practical support to minimise the burden of the disease during treatment.
10. Elimination of all forms of discrimination, during and beyond treatment, in education, vocation and insurance, or in the community. (http://cancercharter.org)

The prominent advocates for TYA's with cancer in the UK is the Teenage Cancer Trust. Formed in 1989, they campaign and lobby for specialist service provision for this age group; have been instrumental in influencing health care policy; and have financed the building of 25 specialist units throughout the UK, with 14 located in principal treatment centres. The principal aims of these units are to enhance survival, through the provision of age appropriate psychosocial support, in order to minimise the physical, psychological and social costs of survivorship. The Teenage Cancer Trust also fund a number of clinical and allied health professional posts, for example, clinical nurse specialists and youth co-ordinators, with other health professionals becoming affiliated to the charity once they commence working on a specialist TYA unit. To date, no thorough evaluation had been carried out on any of the specialist units funded by the Teenage Cancer Trust. Thus, along with the advent of new TYA cancer policy, it was timely to begin evaluating these unique care services.

What are Psychosocial Needs?

Cancer occurs within a multifaceted web of social relations. Thus, both diagnosis and treatment of TYA's with cancer amounts to complex biopsychosocial phenomena. Whereas the biological dimension can be understood more readily, the 'psychosocial' dimensions can be vague, and give rise to a range of interpretations that can confuse and narrow understandings. For the purpose of this evaluation, 'psychosocial' is understood in a broad manner, and relates to the underlying needs that young people and their families and carers require to enable them to cope with a cancer diagnosis, and to continue to cope with their everyday lives throughout the treatment process and beyond. It is these underlying needs, that if not addressed, can lead to psychological distress. A helpful interpretation of the term psychosocial can be found in an NHS commissioned study, carried out by Thomas et al (2001):

> *Psychosocial needs are embedded in features and qualities of life and social relationships that, from the viewpoint of patients and informal carers, are necessary, important, or critical to their psycho-emotional ability to live with the knowledge and social consequences of cancer, and thus to their ability to hold themselves and their social worlds together. (Thomas et al 2001, p20)*

This definition of psychosocial needs is useful for thinking about the support that has been established in the Leeds service, where greater emphasis is given to the 'social' in 'psychosocial', than is perhaps customary in other health specialisms.

EVALUATION DESIGN AND METHODS

EVALUATION DESIGN

The evaluation aimed to explore particular aspects of the service from the perspectives of service users, as well as staff. The tenets contained in the *International Charter of Rights for Young People with Cancer,* were used as a guide, and as baseline measurements, with the exception of rights 2 and 10. The evaluation represented a snapshot of the service at Leeds, i.e., research occurred at a specific time, in a specific place, and with specific participants. Although individuals will understand their experiences differently, and hospital contexts will vary from region to region, it was hoped that findings could be extrapolated and help to inform other services, allowing them to adapt or develop their services to deliver best practice, patient centred and age appropriate care.

Research ethics approval was obtained from Coventry University, and service evaluation/ development approval was obtained from Leeds Teaching hospitals.

Why Leeds was Chosen for Evaluation

Leeds was chosen, in the main, as it has developed organically, and is considered a good example of best practice. The Leeds service was first established in St James' Hospital in 1998/99, with one social worker and a nurse specialist. The service's objectives were to provide holistic and peripatetic support for teenagers and young adults aged 13-25 years old. By 2004 two further nurse specialists, a psychologist and an activities co-ordinator had been added to the service (Pini 2009).

Evaluation Objectives

This is the first systematic evaluation to be conducted at any of the specialist units funded by the Teenage Cancer Trust, and its aims were:

- To evaluate the specialist support offered to teenagers and young adults with cancer, and their families and carers.

- To identify examples of ‘good practice’ in meeting their needs.
- To identify any areas amenable to improvement, and/or any unmet needs.

METHODS

Sampling

A purposive sampling method was used, whereby participants were selected strategically and on a stakeholder basis. This method of sampling, rather than aiming for statistical representativeness, sought to reflect the diversity of young people who had been diagnosed with cancer and used the service. In all, 40 stakeholders were interviewed, consisting of 14 young people – five young women and nine young men, aged between 15-25. Young people had been diagnosed between ages 10-24 and all had finished treatment. Six young people had been inpatients in the 18-25 TYA service and one had been an outpatient; six young people had been inpatients in the 13-18 TYA service, and, again, one young person had been an outpatient. In addition, Six parents and two partners were interviewed – six women and two men, aged between 22 and 49. Demographics such as education, employment and travel distance to the primary treatment centre were also documented (see appendix II).

Recruitment of participants was mediated through CNS’s and other allied health professionals. The specific time frame measured was from the point of diagnosis - when patients entered the service, and the end of treatment, i.e., before follow up/after care. Lastly, 20 members of Leeds Hospital Trust TYA medical oncology staff, and allied health professionals were interviewed, all aged between 20 and 59. All participants were given background information, and informed consent was obtained (see appendix I).

All service user participants were given pseudonyms to protect their anonymity. Whilst staff, because of the gendered nature of health work, and to protect their anonymity, are referred to only as ‘staff’.

Data Generation

Data generation consisted of two qualitative stages. Firstly, participant observation was carried out over a period of two months. This was similar to ethnographic research, where researcher involvement and familiarity helped staff become used to, and relaxed with the presence of a researcher, which in turn helped to promote positive relationships and a sense of involvement in the service itself. Participant observation included attending patient-doctor consultations, attending ward meetings, shadowing key members of staff, and attending meetings such as multidisciplinary therapeutic and psychosocial meetings.

Secondly, semi structured, in-depth individual interviews were conducted, with each interview being audio-recorded. The interview process provided participants with the opportunity to articulate their own views and identify their own priorities and needs regarding provision and delivery of care (Mulhall et al 2004). Young people, parents and partners were asked open-ended questions about their experiences of the service and the support they received (see appendix I). Whilst staff were asked open-ended questions about the service they delivered, and any challenges they encountered (see appendix I).

A visual map outlining all the facilities and the support and specialist services, was given to each service user at the start of the interview as an aide memoir (see appendix I). Three young people and two parents were also consulted on the interview questions and the map of support and services before they were used.

Analysis and Data Coding

Analysis closely resembled qualitative content analysis (Weber 1990), carried out evidentially and illustratively (Mason 2002). This method is often utilised when the main analytic categories are known beforehand and have already been formulated for exploration. This method also allowed for further themes and/or analytic variables to be created that did not fit the existing analytic categories (Weber 1990). NVivo 9 qualitative software was used to assist with the management and analysis of data.

A first level, line-by-line coding system identified master themes and concepts that went on to form the basis of analysis (Miles & Huberman 1994). Once these master themes were created, they were broken down into further sub-themes, or second-level categories. After checking for inconsistencies and/or developments that had occurred during the full period of coding, an independent assessor verified the themes and concepts produced. The next step was to systematically read through each theme and subtheme, and merge those that shared similar characteristics.

Limitations

The young people interviewed in this study ranged from between two months and four years from finishing treatment. As a result, this may not reflect any recent changes that had occurred in the service.

MEETING DESIRED PATIENT OUTCOMES: SERVICE USER PERSPECTIVES

CHARACTERISTICS OF THE SERVICE

There is a growing body of research that points to teenage and young adults with cancer requiring specialist, age appropriate care in relation to clinical expertise, social and psychological support, and specially trained staff. This, in part, stems from poorer outcomes for this age cohort, and is underpinned by a National NICE evidence review (2005), and NICE IOG guidelines (2005) for commissioning services. Research to support how specialist units lead to improved outcomes for this age group is in its early stages, nevertheless a body of literature is beginning to emerge (Kelly & Gibson 2008; Taylor et al 2011; Smith et al 2004), and it is envisaged that the findings from this evaluation will help to build on this body of evidence from a qualitative, and patient centred perspective.

Helpful guidelines for the implementation of care for TYA's are provided by a number of prominent leaders and scholars (Kelly & Gibson 2008; Lewis & Morgan 2007; Ramphal et al 2011; Smith & Case 2012). For example, the guide supplied by Ramphal et al (2011), outlines three domains of care for a quality service. Firstly, medical expertise, which would include access to both paediatric and adult expert care across the full range of cancers, and access to clinical trials. Secondly, a range of psychosocial support from a multidisciplinary team trained to work with this age group, including access to information about the cancer diagnosis, treatment and late effects; social support covering the maintenance of social networks and peer groups, support with education, employment, finances and future social issues such as obtaining different forms of insurances, mortgages etc; as well as psychological support. Thirdly, an appropriate inpatient and outpatient physical environment, with technology enabling communication between patients, patients and health care teams and between individual members of health care and psychosocial teams. In addition the model should be accessible, affordable and patient friendly (ibid p2320).

The first section reports on young people's, families' and carers' experiences of the specialist unit at Leeds. It draws together the different components that have developed to provide specialist care, and evaluates them from a service user perspective, using the charter of rights as a baseline measure. As such it starts with young people's experience on the wards themselves and examines the facilities and environment. It then looks at social relationships on the wards, including peer support and maintaining social networks. After this it explores different types of information sharing, and finishes with the support received by family members and carers.

STAYING ON A SPECIALIST TEENAGE AND YOUNG ADULT UNIT

General Opinions

Young people, their families and carers all reported how positive their stay on the TYA wards were, with the following extracts typical of general opinion:

> *We've seen all three and all three of them are absolutely fantastic, they are brilliant! And all the nurses, all the specialist nurses downstairs on the ward, again they can't do enough for you, you know, I've got utmost respect for them and they're absolutely fantastic. (William, Parent)*

> *Lucy: Even the nurses they just seem to have a little bit more time for you don't they? (Lucy, YP)*

> *Joe: Yeah, it was like, on a night time if I was still sat awake, I'd have a conversation with them about what was on telly or something, it might pass twenty minutes. I don't know it just made it go that little bit quicker. (Joe, YP)*

> *Everyone's always been really helpful and sort of listened if I ever said anything, yeah. Yeah the people are the best thing about it. Really comforting, I think. I used to be really afraid of sort of when I get older like going to hospital sort of thing, I had a fear about it, but once I came and realised how comfortable they made you... (Ryan, YP)*

Daily Regimes

Young people were very happy with their day-to-day experience on the TYA wards. None of the participants suggested any difficulty with family and carers sleeping over on the units, and all were very happy with the ease and smooth processes surrounding this. All participants also reported a respect for their privacy, such as being able to pull their curtains round their bed, or not being interrupted in their rooms. Unlike other wards, daily regimes like being woken up, and meals being served at specific times were also absent, and young people found this to be of considerable benefit, especially those that had experience on non-TYA wards. In addition, young people were, in the main, left to sleep as much as they needed, as Gemma points out:

> *Yeah, there were no... they didn't wake you up or... it was just like being at home really. (Gemma, YP)*

When young people's sleep were interrupted, it tended to be for clinical procedures, or, as Poppy states:

> *if someone did come and wake me up, which they never used to, they only used to come and wake you up if you'd been sleeping a lot, like about 12 o'clock they used to come and wake me up and: "No Poppy, you need to get out of bed now because the more longer you sleep the more it makes you tired". (Poppy, YP)*

Poppy's extract suggests that when young people had to be woken, they were also given an explanation, which was evident of good communication skills.

Hospital Food and Meals

Food is an important feature in young people's recovery. However, the side effects of some treatments are nausea and lack of appetite. In this evaluation, food featured highly in young people's experiences on the wards, and included discussions around mealtimes, dieticians, and the standards and variety of food available. Although young people had mixed responses to the standards and variety of food, all participants reported that they could eat whenever they wanted, and were happy with the flexibility of meal times, and the alternatives available to standard hospital fare. Indeed, a number of participants were considerably impressed with the extra mile that staff would go to, in order to encourage young people to eat:

> *The people that brought it round were fantastic, I mean we had one who used to get a MacDonald's for him at lunch, and that's the sort of people they are ... "Oh I'm going out for my dinner so I'll call at MacDonald's and I'll bring it in". And they do stuff like that, and it's like wow! To me that's exceptional service! (William, Parent)*

> *The woman that sorted it out, all the food, she'd arrange to wake me up and she used to come on a morning and say "do you want a tea or coffee?" or "do you want something to eat?" so she used to do it when I'd wake up because I couldn't go out and make it myself. (Poppy, YP)*

> *And [Name],she tried her best, didn't she, to tempt you in everything she possibly could food wise. [Name] used to come round and like... she was like their personal chef! She was fantastic! (Lauren, Parent)*

Hospital food itself, however, did not receive such positive responses. When participants were asked about any changes they would make to the service, a number highlighted food as an area for improvement:

> *The food menu for kids, that got a little bit mundane, it was the same menu all the time. Nothing wrong with it, but I found with James that his taste buds changed and he only wanted certain things and that…. you get the same thing every day, so that could be jazzed up a little if anything. (William, Parent)*
>
> *Maybe like hospital food and that… if it could be like different choices on the Teenage Cancer Trust ward, or something like that, because the hospital food is horrible and I wouldn't even want to have it! (Matthew, YP)*
>
> *The food was awful, even the smells of the food made me feel really ill! I don't even know if they could improve-well they could improve the food I should think, because my girlfriend used to bring burgers from MacDonald's. I liked them at the time, so you know, a nice plain burger, nothing too strong to put me off. (Michael, YP)*

To counter young people's lack of enthusiasm for hospital food, a number of alternatives were available, including kitchen facilities on each of the TYA wards. A number of participants reported family members and partners utilising these facilities to make more appetising snacks:

> *There was a kitchen there that the patients or carers could use, I had a lot of things there, my mum used to prepare meals for me rather than have the food there. I hate hospital food! (Harry, YP)*

Another solution for participants was bringing in food from outside of the hospital, either from home, or from commercial outlets. Other alternatives were on-site dieticians that the TYA service drew upon. However, the dietician was often seen as an unwanted necessity for many of the young people:

> *Yes, she [Dietician] was always at me, all the time: "you need to eat this", and she was giving me all these food like drinks that have got loads and loads of calories in them, and she always told me to drink them, but I didn't, they tasted horrible … You just don't feel like eating at all, like you feel full all the time, it's weird. (Rebecca, YP)*

Clearly, the dieticians' role could be difficult at times. Encouraging young people to eat when they have no appetite can be challenging, therefore high levels of communication, negotiating skills, and the ability to relate to young people are distinct advantages.

Lastly, food vouchers were also an option. This system involved the exchange of vouchers for meals at hospital cafeterias. Although many participants, especially those based on the 18-24 ward, reported taking their meals at the hospital cafeteria, many were initially unaware of the food voucher system:

> *I didn't really know they were available until later on! If I'd…. probably known about that earlier then I could have gone down to the canteen and picked a few different things, because when you're on treatment I'd describe it as feeling hung over, you don't really feel like eating but you know you have to eat (Matthew, YP)*

Food and diet is a subjective area, and hospitals must cater for a wide variety of tastes, which can be a difficult task within both the current economic climate, and the structural changes that have developed in health care. Nevertheless, a healthy diet and intake of nutritional food is a crucial aspect to recovery from illness. There is also a body of research that suggests important links between diet and state of mind, which contributes to recovery (Anderson 2002; Kristal et al 1997). At Leeds, it was evident that a number of alternatives to standard hospital food had developed on the TYA wards. In particular, the specific employment of ward catering staff appeared to be of considerable benefit, with staff going to great lengths to encourage young people to eat. Similarly, kitchen facilities on the wards allowed carers to make snacks that were more appetising for young people.

Facilities and Physical Environment

The facilities on the TYA wards are extensive, and aim to foster as near a sense of normality as possible. Facilities consisted of single en-suite rooms and three and four bed bays, each with space for sofa-beds for visitors. All rooms had televisions with connections for computers/iPods etc. Each ward had kitchen facilities; complementary therapy rooms, parents' rooms; studies or quiet rooms; recreation rooms with televisions, computers and games consoles, juke box, pool table and comfortable sofas. Young people and their significant others were, without exception, highly appreciative of these facilities:

> *I still wanted to go home but there was a lot more I could do, I could go and put a DVD on, I could go and sit in the little room or play on the computer or do something different, whereas on the other wards you can't really-you can't do anything. (Joe, YP)*
>
> *It wasn't uncomfortable or anything like that, I didn't feel sort of, out of place, if that makes sense? we had bedside tellys and we could take the laptop to the bed for us to use, and what have you. (Jordan, YP)*
>
> *It felt like your home! (Zoe, YP)*
>
> *The services are just absolutely out of this world! (Lauren, Parent)*

Social networking was also important to young people, and internet access and the use of mobile phones enabled them to maintain contact with friends outside of the hospital. Unfortunately, the mobile phone signals were intermittent on both of the TYA wards, but only one young person mentioned this as a problem. It is evident that these age appropriate facilities contributed significantly to maintaining a sense of normality. The home-from-home atmosphere, and the attention to creating as non-clinical environment as possible, confirmed how significant and beneficial this was for young people's recovery. In addition, the environment benefited family members and carers, as William, a parent, succinctly points out:

> *"The environment is so key, and that made it a lot easier from an emotional point of view."*

Challenges

In general, there were very few areas of concern, regarding the facilities and environment. However, the concerns that were voiced by staff were confined to the 13-18 TYA ward, and related to the facilities causing potential isolation, as well as a recent relocation of the 13-18 years service.

Isolation

The flip side of creating an age appropriate environment, is that some young people can stay in their rooms for long periods of time. This caused issues for one participant, who, although he thought the facilities were very good, also felt isolated at times:

> *But yeah they've got everything they need in these side rooms, you never really need to come out of them. Which again, is keeping everyone isolated and not… they won't like bump into each other and talk to each other so… less friendly place. (Harry, YP)*

The same can also be difficult from a staff perspective. Having a range of facilities around each bed could mean that young people had little encouragement to get up:

> *we've got everything we need here, which is fantastic but the downside of that is that around their bed they've got absolutely everything so they don't need to get out of it. (Staff)*

To combat feelings of isolation, the youth co-ordinators played a key role in encouraging young people to interact with peers, and to join in with activities outside of their rooms. These practices carried out by the youth workers added to their responsibilities, and contributed to the high value placed on them by other members of clinical and allied professional staff.

Relocation and New Environments

At the time of evaluation, the TYA Unit had undergone major changes. Originally, the 13-18 and 18-24 units were located within the same hospital, however, as part of the establishment of a children's hospital, the 13-18 TYA ward was relocated at a different site, approximately two miles away. Although young people and their carers remained highly appreciative of the environment, staff have had to adapt to significant reorganisation. As a result, some members of staff were concerned about the new environment and physical layout. In terms of the environment itself, staff pointed out that windows and natural lighting were absent on the new ward. This meant the ward was dark, did not look out to the 'outside world', and could feel claustrophobic:

> *I mean you know unless you go out in the day you've got no idea what the world outside is doing or you know, even if it's actually daylight still, and I think a lot of the teenagers are affected as well, really struggle with that. I mean we've obviously got that quad angle right in the middle but actually because of the way the building is it's actually very dark. (Staff)*

Despite the concerns of staff, it is possible that lack of natural lighting caused more difficulties for staff than it did for young people, as it was not commented on by either young people or their families. Nevertheless, young people were discussing their experiences retrospectively, and many of them had been inpatients on the old 13-18 TYA site. Therefore, it cannot be assumed that young people had no concerns in this area.

The physical layout of the relocated ward had caused problems for a number of staff, which can be summed up as follows:

> *We can't see a few of the patients, you can't hear the buzzers down the corridor, we can't hear the buzzers that are going in the bay when the door is shut, so on a night parents will have to wake up, or patients will have to wake up and press the buzzer to get the nurses attention because we just can't hear them, so from that side of it that's worse. (Staff)*

Other concerns were directed at the day-ward and outpatient waiting room for young people. This waiting room is very small, and located within the larger waiting room for younger children. When staff were asked what changes they would make to the service, most mentioned these areas:

> *Big proper area for teenagers so they didn't have to mix with too many small children, and they could do what they wanted pretty much, which is a bit difficult in that tiny little room. (Staff)*

> *We have got designated areas now for the teenagers, and as our teenage population who are being treated are growing, we soon outgrow the space that we've got, we probably need a bigger area. (Staff)*

Unfortunately, there is little to be done about the physical building, and, as staff pointed out, they have had to be creative and adapt to their new surroundings.

What, perhaps can more easily be solved, is a situation concerning a bath on the ward, which is too high and could cause problems on a day to day basis. Patients can only bathe in this bath if they are able to stand on a stool and step over and into the bath, as it cannot be lowered. This problem was mentioned by a number of staff, but they were not confident in knowing who to contact to resolve it.

In relation to the 18-24 unit, which was completed in recent years, its facilities were overwhelmingly deemed excellent. Only one member of staff voiced any concerns, and this was aimed at a shortfall of facilities for partners and parents around accommodation and washing facilities. Family members and carers were able to sleep over on the unit, but there was also hotel accommodation in the same building. However, the numbers using the hotel were on the increase, and had become harder to access, which, on occasion, had caused problems.

With regard to personal hygiene facilities, staff pointed out that there were no parent/carer showers, other than a toilet with a wash basin. Carers need to feel clean and refreshed if they are to continue to contribute to the care and wellbeing of the young person, and this is especially pertinent when people have to travel significant distances. The lack of personal facilities were usually negotiated and overcome, but this required time and resources from already stretched staff.

To sum up, without exception, young people, their parents and carers were highly complementary about their stays on the TYA Units, and were unanimous in their praise for the exceptional environment and facilities provided. In addition, it was recognised that the dedication and commitment of the TYA team was instrumental in providing the outstanding care they received. To understand in more detail how the specialist TYA wards contributed to young people's recovery, it is helpful to examine their experiences with other non-TYA paediatric and adult wards at Leeds, as well as at other regional hospitals.

Inpatient Stays In Other Regional Hospitals

Alex was diagnosed with cancer at a hospital in a different town within the Yorkshire and Humber region. He stayed on a paediatric ward, where his parents found the systems and processes difficult:

Cameron: *They're not very efficient. We was ringing up for blood results and they would say "oh, you're gonna have to wait."*

Megan: *They could be quite snotty with you,*

Cameron: *It was, it was awful! (Cameron & Megan, Parents)*

This contrasted significantly with their experience on the 13-18 TYA ward at Leeds:

Megan: *You get like your own nurse and she was brilliant, I didn't feel uncomfortable asking for anything.*

Cameron: *We rung around ten, and the middle of the night you know, early hours in the morning, there was always someone there to... you'd always get somebody or somebody would ring you back in minutes, it was brilliant!*

Megan: *Yeah, everybody's... there's not one person here that hasn't been brilliant, you can ask anybody anything and if they don't know they will find somebody that knows. I just don't have a single complaint and it's amazing what people do! (Cameron & Megan, Parents)*

Megan and Cameron were considerably more happy with the ward at Leeds, and in particular, the fact that someone was always on the end of a phone to offer information and advice. The 24 hour availability helped to instil confidence in the expertise and commitment of staff, which was an important feature of the service.

Young people also discussed the general atmosphere at hospitals in other towns. Alex compared his experience on a paediatric ward in another town with the 13-18 TYA ward:

Carole: *So when you were on the [Name] ward, can you tell me what it was like?*

Alex: *Boring. There wasn't a lot to do ... The ward here seemed a lot more calm, I don't know... To be honest I would rather travel the extra however many miles it was to come here, because everything is a lot... the whole place seems a lot better than it was in [Name], a lot friendlier and seems a lot better all round. (Alex, YP)*

With reference to general adult wards, Jordan and Ryan compared their experiences in other towns with the 18-24 TYA ward:

> *Yeah it just seems so much more tense on the adult ward, I mean I was glad to get out of there to be fair. (Jordan, YP)*
>
> ***Ryan:*** *[Town] was a lot more kind of din-not dingy but do you know how you'd expect hospitals to be in the 80s or something, that kind of thing.*
>
> ***Carole:*** *So it was showing its age?*
>
> ***Ryan:*** *Yeah... just more sort of... less comforting, you know? Less sort of nice-pictures-on-the-walls, kind of thing, it was all kind of... It wasn't very colourful! (Ryan, YP)*

It is evident that Alex benefited from the activities and distractions on the 13-18 TYA ward, which helped to alleviate his boredom. From his stay in another hospital, Ryan recalled the tired decor, and the wear and tear in the surroundings. Importantly, all three young people used positive adjectives to describe and compare the atmosphere of their different hospital experiences. Alex found the Leeds 13-18 TYA ward "friendlier", and "more calm", indeed, he states that travelling the extra miles to Leeds was preferable. Ryan also found the 18-24 ward more "comforting", and Jordan remembers how tense the other hospital ward was.

These three young people were ideally situated in their ability to compare their stays in other hospitals with their subsequent stay in the TYA Service. This is important, as it flags up the competing perspectives highlighted in Pearce et al's (2010) study between young people and Commissioners. Pearce et al found the general views of Commissioners were that "the decor of a unit was irrelevant; the importance was clinical care." (ibid p7). However, for Ryan in particular, the memory of the tired decor contributed to his negative experience, which suggests that colourful and more homely environments are more important to young poeple than commissioners believe them to be.

The positive terms used to describe the TYA environment and atmosphere were also significant, as they endorse and lend support to the funding of these specialist units by the Teenage Cancer Trust. They point not only to the beneficial effects that colourful furnishings provide, but also to the TYA team as a whole and their endeavour to maintain a sense of 'normality'.

Inpatient Stays on Adult Wards in Leeds

Young people also reported negative experiences on non-TYA wards in Leeds. This was particularly true in relation to adult wards. For example privacy, sleep regimes, and set meal times were far more rigid on adult wards. They were also critical of the mood and atmosphere, as Joe points out:

> *Well I've stayed in different wards before when I've had operations, like on [ward No], it's a lot different, everyone seems to be in bed. I don't know, and the nurses, everyone seems to be really happy up at [TYA ward]. (Joe, YP)*

As well as Joe alluding to a less happy atmosphere on other wards, he also comments on how "everyone seems to be in bed", which was also discussed by other young people:

> *So there was this woman across from me and she was practically-when I first walked in, she was sat up and she was asleep sat up, I thought "oh my God what am I doing here?" I didn't like it because we had to share all the bathrooms, they were old, you know, I just didn't want to be surrounded by that. (Poppy, YP)*

For both these young people, being in the company of older people, and people who adopted a sick role status was problematic, both felt uncomfortable, and both felt happier when they were moved to the TYA ward.

A lack of communication on non-TYA wards was another issue for young people:

> *I mean I had no idea what was going on at the time, I had my operation and they just left me there, I didn't know what was going on and they didn't talk to me for ages. (Michael, YP)*

Ward regimes were also difficult for young people on adult wards, with the main issues being woken up early in the morning; meals being inedible, and served at set times; boredom; and lack of privacy. Lack of privacy is highlighted by Joe, which is typical of participants' experiences:

> *Because when I was in there, I had loads of things, I just wanted my curtains shut and just to be sat on my own, I couldn't move or do much or anything else and sometimes the nurses would come and open the curtains and then just walk off after you've told them to shut it and stuff. Not that they were doing it on purpose, just because they had other things to do ... And I was just ready for signing myself out, because I thought-it felt that bad I couldn't stay there, it was just one thing after another went wrong all the time. (Joe, YP)*

Joe's extract, again, demonstrates a failure to act upon, or hear young people's needs, and his level of distress led to considering signing himself out of hospital.

Some staff on adult wards did not have the communication skills required to relate to young people, as Jennifer states:

> *They're more equipped for it up there on [TYA ward]. I found... I don't know whether I should say this, but I found one of the nurses on [ward No] a bit abrupt really, they sort of didn't come down to Gemma's ... well she didn't, come down to Gemma's level. She was an older nurse. The younger ones seemed fine, it was just this one particular nurse and she was a bit abrupt. (Jennifer, Parent)*

Young people can be challenging and difficult, but the age appropriate skills acquired by specialist TYA clinical staff to deal with this age underpins the delivery of care. More importantly, these skills can aid the young person's treatment and recovery, by alleviating stress, emotional distress and encouraging concordance with medication.

Inpatient Stays on Paediatric Wards in Leeds

Two young people, Zoe and Rebecca, were diagnosed at ages 12 and 14, respectively, and both stayed on paediatric wards for a short time. Zoe felt out of place with the younger children:

> *I was the oldest out of all the kids, so it was really like an odd age. So I used to-obviously I wasn't allowed in the day room, but I had a playroom, but at 12 do you really want to go sit on chairs [puts hand near the floor] about that high, and draw! (Zoe, YP)*

Rebecca's experience was slightly different. When she was diagnosed. There were no beds available in the TYA ward, and, despite being 14, was compelled to stay on the paediatric ward. For Rebecca, it was the sight and knowledge of very sick children that was upsetting:

> *When I was diagnosed there was no room on [TYA ward], so I was put into [ward] first but I just stayed in my room the whole time because I didn't want to go out on the corridor and see all the poorly people because that would upset me, so I stayed in there when I could ... You just hear little kids screaming a lot when you're on [ward]. (Rebecca, YP)*

Although, these two young people's experiences are not as extreme as participants' experiences on the adult wards, their unhappiness was evident. Both participants lacked interaction with their peers and both had to adapt to the situation. For Rebecca, who tended to stay in her room, this self imposed isolation can instigate a sense of loneliness, which may not be conducive for recovery. Fortunately, both participants were eventually able to move to the TYA ward, and both felt they benefited enormously once this was accomplished.

Recommendations

1. Ongoing Education and awareness of TYA service to all other adult oncology wards. TYA service to be alerted and visit young person during their stay on other adult wards.
2. Details about food vouchers to be included in initial information packs. Dieticians to be made aware of food vouchers
3. Variation of food. Lighter snacks, such as salads.
4. Furnish staff with list of contacts for any troubleshooting concerning ward facilities.

SOCIAL RELATIONS: HEALTH PROFESSIONALS, SOCIAL NETWORKS AND PEER SUPPORT

Privacy in Clinical & Medical Consultations

Allowing young people the time to speak with their consultant on their own can help to foster and maintain a sense of independence and control over their illness. There may be subjects that the young person wants to discuss that could be difficult when significant others are also present. For example, advice on fertility, sexuality, drug use and harm reduction, and so on. Young people may also want to protect significant others from certain aspects of their illness. Zoe, age 18 now, sums this up perfectly:

> *I go into [Name] by myself, because I prefer it on my own… because I feel I can't say things in front of my parents, I'm trying to feel like you're protecting them even though you're not because they don't like it, but it's-I get to have my own decisions, and it's a lot more independent, I could do what I want. I like to talk about everything, whereas I feel like when they're with me I can't say, because I'm trying to protect them because I don't.… it's stupid really because I'm the kid so I shouldn't be, but I feel my choice is now to come to clinic on my own. (Zoe, YP)*

In the observational stage of this evaluation, it was noted that young people seldom spent time alone with their consulting physician. Privacy is an important aspect in all young people's development, but for young people with cancer it constitutes an important feature of age appropriate care, and was acknowledged by staff:

> *One of the things I always find difficult is where I've got a teenager, 14 and upwards, and a parent, and where you can see the teenager wants to ask a question but the parent always jumps in … or wants to hear what the teenager or I might have to say to one another. (Staff)*

Dilemmas regarding how to involve the family, whilst also protecting patient centred care, and enabling young people to take responsibility and control tended to be incorporated into the regular working practices of nursing staff and allied health professionals, but not always by physicians. However, this is an important feature of TYA care, as the sense of independence young people experience when exercising time alone in any consultation, not only helps to develop independent decision making, but can also support young people in managing their illness, and assist with transition to the older TYA service, and, eventually, adult services.

Non-Concordance and Challenging Behaviour

One of the skills needed to care for young people is an understanding of challenging behaviour, which can often manifest through non-concordance with treatment. Two young people discussed their behaviour around non-concordance, without prompt, which suggests its significance as a potential area where problems can arise.

Rebecca was 14 years old when she was diagnosed with cancer:

> *I knew that it was for the best, like to take it and even though I said to the nurses… you know like when you don't want to take your tablets and stuff? Even though I said to the nurses I knew I had to take it so always ended up taking it, they were like "you need to take it, you're not going to get better unless you take it." But I always like… I knew that I could just refuse, but I also knew that I had to take it … Then in the end I always took it. (Rebecca, YP)*

Rebecca looked back to her time of treatment, and although she understood that medication would help her get better, she wanted to exercise some form of control. Thus, Rebecca, effectively, negotiated with herself, and with clinical staff, when she would take the medication, which helped shape her coping strategies.

Poppy was 20 when she was diagnosed with cancer. She contracted MRSA and had to be cared for in a room by herself. Poppy discussed how difficult having a cancer diagnosis was, and how she felt isolated. She believed her behaviour was challenging on two levels. Firstly, her refusal of treatment:

> *I refused treatment, I was like "no! I'm going! I don't want it!" I refused to get my line in, I was like: "I don't want it!" I was a bit nasty, but they were lovely. Not once did they say: "No, shut up, put up with it." They were really nice. (Poppy)*

Poppy's expectations were that clinical staff would be firm and unyielding, but clearly this was not the case. Secondly, her depression and feelings of isolation fostered a strong desire to leave hospital:

> *I got really depressed at one point, really depressed. I just wanted to go, I wanted to sign myself out. I wanted that form so I could then go. I was just getting fed up of it, and they were like: "Poppy, you need to understand that, you're poorly, and if you go, you could die because you've got cancer." I just got depressed and they called the psychiatrist to come and speak to me. And then [Name], I think she's like a worker on that ward, she was lovely, she kept coming in every day, because I was there for five days every two weeks, just to see how I was, and like if I wanted anything, because I had to be on my own in that room. I couldn't go out and enjoy the activities. So she used to bring me the activities and bring someone to speak to me. (Poppy, YP)*

For Poppy, the benefit of support services and the skills of staff on the TYA ward can be seen in action. The TYA psychologist listened to her, helped her to make sense of her illness, and gave her strategies to cope with it. In addition, the YSC provided much needed companionship, guidance and distraction.

The skills required to care for TYA's were also looked at from the perspective of staff, and they were asked specifically what skills clinical and allied health professionals needed to deliver best quality care to TYA's with cancer. A range of skills were discussed, with the most common being: listening, communication, patient centredness, empowering of the young person, non-judgmental attitude, humour, openness, negotiation, having clear boundaries, patience, understanding, empathy, managing different perspectives, and, importantly, the ability to handle difficult or challenging young people. These skills are clearly necessary, and are in harmony with the above extracts from young people.

What TYA's also need from staff is their understanding of young people's developmental stages. Although the vast majority of staff possessed these skills, the crossover between paediatric and adult care was particularly salient, and could occasionally cause problems:

> *I think they [some staff] struggle with the teenager who is a bit stroppy, knows what they want to do, knows what they don't want to do, doesn't follow the plan of care that you might want to put in their card. (Staff)*

The philosophy underlying paediatric care is a whole family approach. However, adult care has its foundations in a more individual approach, which tends to be directed at the patient. This merging of care for TYA's can be difficult to grasp, especially if staff are used to working with one or the other of paediatric or adult care:

> *If you've been in the job 10, 15, 20 years and you've only ever done things for children with parental agreement, it can be a huge challenge. And the same with adults I would imagine. (Staff)*

The different skills required for meeting the unique needs of TYA's do not tend to be included as standard in formal training for nursing or physicians. Thus, experience gained in either the adult or paediatric realm can be constraining. Nevertheless, these skills can be developed over time, along with strategies to accompany them:

> *And you've got to sometimes take things very, very slowly and just chip away at it. And actually having the teenagers all together you get a good camaraderie and probably acceptance of what is happening to them personally because they get support from the young people around them. (Staff)*

Clearly, different skills are required to care for this age group. Patience is invaluable in helping to bring TYA's on-side, and to make positive decisions around managing their illness, and ongoing staff training is key. Also important, as the above extract points out, is the important role that friends and peers play in young people's acceptance of their illness.

FRIENDS AND PEERS

Social contact with friends and peer groups is an integral developmental factor in the transition to adulthood for all TYA's. For TYA's with a cancer diagnosis, evidence suggests that, after mothers, friends are a key source of support, and maintaining social friendships contributes to positive outcomes, and the ability to form long-term relationships (Kyngäs et al 2001; Ritchie 2001; Whiteson 2003). However, changes in body image, and the self, can affect self-esteem, which can impact on TYA's social relationships. Thus, young people were asked a number of questions about their friends and peers, that focused on interaction with peers on the unit; maintaining contact with peers after finishing treatment; visits from friends; maintaining contact with friends; and friends' understanding of their illness.

Making Friends on the Unit

Making friends with other young people experiencing similar illnesses widened young people's social network, and was of considerable benefit. One key reason for this, was that young people found peers to hold advanced levels of understanding and empathy, which was highly valued. All except one young person interviewed made friends on their unit, and felt they had benefited from it. Gemma typifies the advantages gained by young people:

> *Because they were going through it, they understand what I felt like and we could talk about it, and even though you've got a different cancer they still know what it's like to have everything going on, and having chemo and like, whereas your other friends don't necessarily understand as much. Gemma, YP)*

Some young people also desired supplementary peer support:

> *like sometimes I would wish that there was a girl, like, it sounds horrible, but I don't... but if there was a girl in my situation, a few months ahead of me that I could look up, I could watch her and see how she's progressing so that I know what's going to happen to me. (Rebecca, YP)*

Although Rebecca is reluctant to put other young people in a similar life threatening position, she felt she would have benefited from the empathy, knowledge, information and advice that friendship with another young person who had experienced a similar disease could have brought.

Interestingly, the level of contact between peers after finishing their treatment and leaving the TYA unit was fairly low. Contact, in the main, was restricted to Facebook, the odd email, and bumping into peers at follow-up clinic appointments. The only face to face contact reported was from Gemma, who had met up with her peers at a 'Moving On group'. However, two participants did report that their parents maintained contact with other parents.

Death of Peers

Cancer, as a life-threatening illness, carries the possibility of death, and this is a key issue for professionals to take into consideration when young people become involved with others on a TYA ward. The emotional and psychological impact of death are significant. Three young people discussed this situation and how they managed it. Rebecca was very matter of fact: "*Well unfortunately the guy that I first met he didn't make it, so I can't keep in touch with him*." However, the remaining two young people struggled to deal with the death of their peers. Poppy's first reaction was fear:

> ***Poppy:*** *I did know one girl but she died, I just used to see her, like: "Hi you ok, what you in for?" You know? And then she died! oh God when I found out! Because I just used to see her, I was like: "Oh my god, that could have been me!" And another boy up on the ward, he died I didn't know him but I see his mum. And this girl, she was well known on the ward.*
>
> ***Carole:*** *How did you deal with that?*
>
> ***Poppy:*** *Cried! I was like "Oh my god this guy next door to me has just died!" You know, so.*
>
> ***Carole:*** *And did your friends support you over that?*
>
> ***Poppy:*** *Yeah, she was like "don't worry." You know: "Doctor is saying that you're going to get better, just don't worry." (Poppy, YP)*

Poppy became depressed on the unit, and at certain points refused medical procedures and wanted to leave the hospital without undergoing treatment. It is possible that the deaths around her contributed to her depression. Fortunately, Poppy was supported through this episode by the TYA psychologist, the YSC, the CNS, as well as her friends.

Harry also talked about making friends on the unit, but related this directly with death.

> ***Harry:*** *I think about ten friends, something like that, I spoke to ten people there.*
>
> ***Carole:*** *Do you stay in touch with them?*
>
> ***Harry:*** *They're all dead. I'm the only one left!*
>
> ***Carole:*** *And how do you deal with that? Do you talk to your family?*
>
> ***Harry:*** *I was depressed for a couple of years with survivor's guilt. Somebody had-they died when they had an easier diagnosis than me and that wasn't a fun time.*
>
> ***Carole:*** *So were you trying to make sense of that? Trying to understand it?*
>
> ***Harry:*** *Yeah because as they were all dropping off one by one I was just waiting until it was my turn, I planned my funeral. It didn't happen though.*

Clearly, this situation was very difficult for Harry, and had a profound effect on him. Previously, Harry had mentioned that he felt isolated on the unit, but then went on to discuss why he avoided interaction:

> ***Harry:*** *Yeah it's quite a big place and you don't really see anyone, but then after what happened to the ten people last time, I don't really want to speak to any more patients, just in case.*
>
> ***Carole:*** *OK, so you're wanting to protect yourself, you don't want to have to deal with that*

> *again? It's too upsetting?*
>
> **Harry:** *Or in case I cop off and they feel the same!*
>
> **Carole:** *Do you know what a psychologist is?*
>
> **Harry:** *Yes, I've been told to see a few of them.*
>
> **Carole:** *And have you?*
>
> **Harry:** *No. I think I had two sessions with one, and never again.*

Young people have a tendency to feel invincible, and the death of a young person can be unexpected and shocking. When this happens on a TYA ward, young people are faced with their own mortality, and if this happens on more than one occasion, it is inevitable that young people will want to protect themselves, and may want to protect others. One aspect of protection may be to avoid establishing further relationships. Although Harry accessed the TYA psychological service, he felt this was not suitable for him, and discontinued sessions. One reason for this may be the stigma attached to psychological therapy. Nevertheless, this is a complex and difficult situation for all concerned, including staff who cared for the young man. It was unclear what procedures existed for situations such as this, but it would be helpful if strategies and guidance were available for staff to deal with this.

Friends and Visiting

The findings for friends visiting on the unit were surprising. Although all young people said they were happy with visiting hours and the flexible arrangements, only three of the fourteen young people interviewed had regular visits from friends. Of the remaining eleven, nine had intermittent visits, and two young people received no visits from friends. Explanations for the infrequency of visits are threefold. First, for three participants, the hospital was difficult to travel to, either because there were no direct bus routes, or because the young person lived too far away.

Second, young people regulated which of their friends could visit, and when:

> *Yeah, I didn't want anyone to know, I thought if my hair falls out there's no way I'm wearing a wig. (Poppy, YP)*

> *They [friends] didn't come much because sometimes... I'd only want them to come when I was at my best. If I felt OK I wanted them to come. If I wasn't OK I wouldn't want them to come. (Rebecca, YP)*

> *My two best friends wanted to but I didn't let them, really. I didn't really want to show them this world, and coming to the ward. Even though it would have been fun because, I mean [Name] would have found something for us to do and things, but I just didn't want to risk them coming in and seeing something horrible. I can't stop them from seeing bad things in life ... I didn't want them to come and then they'll see something really horrible that stuck in their mind forever. (Zoe, YP)*

The reasoning behind managing visits varied. Poppy was concerned about the side-effects of treatment on her body, and allowed only two of her most trusted friends to visit. Rebecca was more concerned with how she felt in terms of her health and energy levels. Notably, Rebecca's mum acted as mediator between Rebecca and her friends, and also worked at encouraging her to maintain social contact throughout her treatment.

Zoe, on the other hand, wanted to protect her friends. Although she understood that she couldn't protect her friends from the harsh realities of life, she did not want to be the one to introduce them to the effects of cancer. Moreover, Zoe's decision to protect her friends was made at a personal cost to herself, as she later went on to say: "*Even though it would have been fun*".

These forms of protection can be rather more complex, however, and can be couched in misunderstanding:

> *My two friends who came to visit they said they would have visited more afterwards, but they didn't think I wanted it. And I think people find it difficult to determine whether or not it's me genuinely saying "I don't want you there" or me saying "no you don't need to come."Because I don't want to put them through it I suppose, but looking back it would have been nice if they had visited more, because it was pretty boring (Michael, YP)*

Michael and his two friends acted on what was *not* said. For these three young people, a 'dance' based on accepted norms and politeness was played out, with all three parties making assumptions and behaving accordingly. Because Michael wanted to protect his friends, and avoid putting pressure on them, the result was that all three parties misunderstand each other, and Michael, ultimately, was disadvantaged.

The third reason for non-visits rested with friends' decisions to stay away, from both hospital and young people's homes:

> *I had some very close friends, who I thought were close, who never even talked to me. (Michael, YP)*
>
> ***Carole:*** *Did your friends come and visit you at home?*
>
> ***Natasha:*** *When I first got diagnosed, yes, but after that, not really.*
>
> *(Natasha, YP)*
>
> *It was a bit hard. They did, but they didn't know what to say or do and they didn't know how to approach it. They did come though, and I talked to them but it was more as it got towards the end [of treatment] that they came. (Gemma, YP)*

Although generalisations cannot be made as to why contact diminished, one of the main reasons, in this sample, appeared to stem from friends not knowing how to relate to the young person, once they became ill. This reaction is a common response at all ages to serious and/or life threatening illnesses, but may be compounded by the developmental stages of young people. In that, the levels of maturity, and emotional and social skills to deal with and support a peer's diagnosis of cancer have not developed fully. For example, the nature of the original relationship was formed under particular conditions, which included 'good health'. However, when the young person's circumstances changed significantly, their friends were not prepared for this, and had no readily available 'design' from which to draw upon to guide them on how to behave towards their friend. This could bring about a sense of discomfort, and avoiding the young person appeared to be the easiest strategy available. It is likely, then, that some degree of understanding is necessary if friendships are to be maintained.

Friends' Understanding and Support

Young people in this evaluation experienced mixed responses around understanding from friends. Both Alex and Rebecca were young teenagers when they were diagnosed, and reported that their friends held some understanding of their illness:

> *Well, they'd found out from my mum what had gone on, and they sort of explained it to them in more detail sort of thing. (Alex, YP)*
>
> *I texted my close mates but I think my mum had got in touch with their mums ... But when they came to see me, they didn't act the same, they didn't know how to act around me ... So then I didn't feel like I wanted them to come anymore because they acted strange. (Rebecca, YP)*

Research suggests that mothers are the primary source of support to young people with cancer, with friends ranked second (Nichols 1995; Ritchie 2001). For both Alex and Rebecca, mothers have acted as the main facilitators for maintaining social networks, both mothers of the TYA with cancer, and mothers of the friends of TYA's with cancer. This worked well for Alex, who was slightly younger, and appeared to maintain good supportive relationship with his friends. However, and as discussed above, Rebecca felt her friends did not know how to act around her, which made her feel uncomfortable. Nevertheless, Rebecca's mother continued to encourage her to maintain contact with her friends. Indeed, research suggests that even when healthy friends do not fully understand the implications and circumstances of cancer, their presence and listening to the young person is beneficial (Nichols 1995; Ritchie 2001).

It is likely that the older the TYA, the more social resources they have to draw upon (Nichols 1995; Ritchie 2001). This is consistent with responses from the majority of young adult participants who were 18 years and over at diagnosis. Although, older TYA's exercised selectivity in which friends they informed, they felt that their friends held a level of understanding about their illness, and felt supported by them. One young person compares her friend's support at different stages in her cancer experience:

> ***Carole:*** *And do you think they understood about your diagnosis?*
>
> ***Zoe:*** *Not the first time round.*
>
> ***Carole:*** *The second time round?*
>
> ***Zoe:*** *But the second time round especially [Name], she was amazing because we were both grown up then, or growing up, whereas the first time round I was 12 and didn't really know what it was. (Zoe, YP)*

Having experienced a cancer diagnosis at different ages, Zoe was able to articulate how maturity and her developing social and emotional skills helped both her and her friends in maintaining a supportive relationship.

Although young adults tended to be supported by their friends, two participants felt a sense of loss, too. Michael was 22 when he was diagnosed and felt a number of his friends had let him down by severing all contact:

> *It's just yeah if you tell someone it's very difficult because it's not good news, and you know I only ever joke with my friends and to tell them something serious is well, is extremely difficult... (Michael, YP)*

Michael's experience was compounded by the nature of his relationships, which tended to be based around humour. The act of conveying the seriousness of his illness to his friends was extremely difficult, and the disappointment that ensued affected him deeply.

In a similar vein, Natasha was 18 when she was diagnosed, she felt supported by a small number of friends, and her long-term partner, but many of her friends had begun university in different regions of the UK, and the distance was too far for them to travel. Significantly, Natasha also felt excluded from the social environment associated with universities. For example, she had missed out on 'Fresher's' week, and this retained a significant sense of loss in her memory.

It is clear that the varying forms of misconceptions around cancer gave rise to the majority of young people in this sample losing one or more of their friends. Indeed, there is some evidence to suggest that loss of friends due to misperception is a universal problem for young people with cancer (Palmer et al 2007). A Danish initiative entitled 'Network-Focused Nursing' (Olsen & Harder 2009), is one way of combating this. This intervention involves inviting members of the young person's private social network to a meeting on the TYA unit, usually after four weeks of treatment. This can include friends, family members, teachers and so on. Professionals also attend the meetings to provide information, and to facilitate discussion around the disease, treatment, and side effects. Nurses chair the meetings and can answer questions, dispel myths and misunderstandings, and offer advice on how to support the young person.

Recommendations

1. Consultants to facilitate time alone with young people.
2. Ongoing advanced communication training for staff.
3. Education in schools, to provide peer group with understanding about cancer. With the caveat that the young person's permission is sought in the first instance.
4. Befriending Service.
5. Policy to be produced for protocol around death of peers on TYA units.

INFORMATION SHARING WITH TEENAGERS AND YOUNG ADULTS

As young people develop, so does the need for more information. The requirement for information and the ability to make decisions, however, will always be reliant on the young person's developmental stage, as well as family dynamics and the individual's level of independence and voice within that family (Stavri 2001; Whelan 2003). Nevertheless, developing a positive relationship with the young person and gaining their trust is crucial, which means 'telling the truth' in an age appropriate and sensitive manner (Whelan 2003). Telling the truth, however, can be difficult for family members and carers, who, for protection reasons, may with-hold certain aspects of information. The expertise required for navigating these delicate and sensitive situations rely on high level communication skills and successful teamwork. Not all oncology departments will posses these skills or use this approach, and this can have wide-reaching effects on young people and their families, especially at times when treatment does not work well, or does not progress according to expectations, or when aspects of information are overlooked (ibid).

Research suggests that health professionals can underestimate the information needs of patients and overestimate the amount of information retained and understood (Hancock et al 2007). Therefore, information and concepts should be communicated in an unambiguous and clear way. All cancer patients compose a group whose need for information around diagnosis, treatment and prognosis is important (Steptoe et al 1991), but this holds particularly true for young people who are transitioning from a family based philosophy of care, to that of the more individualised adult philosophy. Information is available from a number of sources. The World Wide Web, for example, now plays a significant role in providing information (Leaffer & Gonda 2000), but it is health professionals who remain the primary source for supplying specific information around treatment (NCSI 2012).

One of the major threads running through the *International Charter of Rights for Young People with Cancer* is 'information'. Information is required for three of the key rights: empowering young people to make informed decisions about their treatment and care; information around clinical trials and their availability; and information around fertility, that is, possible long term effects of their disease and treatment, and preservation of fertility. The following sections assess the application of these three rights, and also identifies finishing treatment as a further area requiring information.

Involvement in Treatment Decisions

All participants interviewed felt happy with their level of involvement in treatment decisions. Information tended to be verbal, but was also given in written form. All participants knew where to go, or who to ask if they needed something clarifying, or had questions, and named their consultant, key-worker, or ward staff. For actual involvement in treatment decisions, participants tended to be equally divided, those who felt they had been actively involved in decision making, and those who felt happier leaving the decisions to the professionals. The following extracts are typical of those who fell into the 'professionals know best' group:

> *They've involved her in everything. I mean it's a bit difficult because we don't know what an alternative is, so it's nothing that you can make a decision about, you either say yeah I'm going to have it or no I'm not going to have it, they are really the only decisions that you can make. That is her path for her treatment. For her cancer, there is a path, and that is the path that you have to go down or you don't go down it and you don't have treatment. (Kate, Parent)*
>
> *Not really, I was just told 'this is what's happening' and when it's going to start, but that's fine by me, they're the professionals, they know what they're doing! (Matthew, YP)*
>
> *No. I just did exactly what I was told, I mean I feel that the doctors know best. (Michael, YP)*

Interestingly, both Matthew (24) and Michael (22) were offered clinical trials, but neither felt this construed involvement in treatment. In contrast, three other young people, when asked about their involvement in treatment decisions, did mention their choices to take part in clinical trials. Other examples of involvement and decision making were around procedures, such as having Hickman lines removed; choosing which chemotherapy to have; and knowing they could refuse therapy and medication. One young woman, aged 15, made the harrowing decision to have an amputation:

> *Like, it was my decision and not anyone else's, to decide about my amputation so then you know… to increase survival rate and… but I could have said no or yes and that was my choice. [Consultant] asked me, so I felt a lot more grown up (Zoe, YP)*

Involving young people in decision making around their treatment is undoubtedly an empowering and important aspect of TYA care and, although half of participants stated they were not involved, it does appear to have been an option open to them, rather it was preferred not to be taken up. This, in itself, could be constituted as choice, i.e., actively choosing to hand responsibility over to the clinical professional.

Clinical Trials

Outcomes tend to be better for young people who are involved in clinical trials, however, TYA's, in particular, older TYA's, are significantly under-represented in clinical trials compared to other age groups (Bleyer et al 2006; Burke et al 2007). Analysis from Whelan and Fern (2008), mapped a decline into clinical trials after the age of 15 years. They found that 56% of children aged 5-14 in England, Scotland and Wales were entered into trials, however for TYA's aged 15 to 24 the figures dropped to 20%. Reasons for this are multi-fold, but include lack of information given to TYA's, lack of available trials, reluctance for TYA's to enter trials, restrictive criteria around age and eligibility, rarity of cancers; and the place of care (Burke et al 2007; Whelan 2010; Whelan & Fern 2008). The culminating effects of these factors result in a dearth of information and regimens for treating older TYA's, compared to other age cohorts (Whiteson 2003; 2005).

Of the six young people aged 15 and under when they were diagnosed, five were placed on clinical trials. For young people aged over 16, four of the eight were offered, and placed on, clinical trials. That more young people were entered into clinical trials at Leeds is in line with their high regional ranking in relation to clinical trials participation, which are well above national averages. In short, all participants who were entered onto trials were very happy with the amount of information they received.

Fertility

Fertility and future parenthood are significant personal issues involving ethical, psychological and social considerations (Whiteson 2003). As young people reach adulthood, choices around whether to become biological parents (or not) usually come into being, but for young people with a cancer diagnosis, fertility choices can be unexpectedly threatened. As such, one of the rights for young people includes fertility preservation, as well as counselling around the short and long-term effects of cancers and treatments. From a medical perspective, the latest NICE guidelines on fertility and treatments (May 2012), has a chapter directed at people diagnosed with cancer, and recommends the cryopreservation of semen, oocytes, embryos and ovarian tissue for all people with cancer who wish to preserve their fertility, including adolescent girls, as well as boys. From a more social perspective the making public of fertility, and by default, sexuality, can challenge cultural, family and relationship sensitivities, making it difficult to broach and discuss. For example, it is usual for parents to protect their children from distress, and, depending on the age of the TYA, parents may also attempt to withhold certain aspects of information, including that of (in)fertility (Crawshaw & Sloper 2006; Whelan 2003). Other problems include treatment effects deterring partners from forming intimate relationships, and young people worrying about the health of their future offspring (Crawshaw & Sloper 2006; Zebrack et al 2004).

The information young people received around fertility in Leeds varied, and analysis revealed two distinct patterns, concerning younger TYA's and young women aged 17 and over. Firstly, being diagnosed in the early teens meant how, and from whom, young people received information could be inconsistent. Secondly, if young women aged 17 and over were *not* referred directly into the TYA service, this could lead to lower standards of information. This section reports separately on both groups.

Younger TYA's

Five of the six younger TYA's interviewed received fertility information, with one of the four boys preserving their sperm. The table below details how and from whom fertility information was received.

Table 1

Name	Age at Diag.	Fertility Info Rcvd	Who informed Young Person	Who was Present	Preservation Offered
Alex	12	Yes	Parents		No
Harry	13	Yes	Parents		No
James	14	Yes	Consultant	Parents	Yes
Kieran	13	Yes	Consultant	Parents	No
Rebecca	15	No			No
Zoe	15	Yes	Consultant	On own	No

Two young people were informed about fertility from their parents. Alex reported that his parents had talked to him about fertility after his treatment was complete:

> *They told my parents but my parents told me afterwards. … There's a lot of stuff like that, that they didn't tell me, because they didn't want me to worry sort of thing. They thought it would make it worse. But once I'd finished my treatment they told me, which I think is probably the best way. (Alex, YP)*

Alex reasons that, due to his young age, his parents made the decision to keep fertility information from him so as to avoid any additional distress, and appeared satisfied with this at the time of interview. However, one young person was dissatisfied with fertility information being shared with his parents first:

> ***Harry:*** *They didn't talk to me about it, they talked to my mum about it. That was quite awkward!*
>
> ***Carole:*** *What, talking to your mum about it? Or them talking to your mum and not talking to you?*
>
> ***Harry:*** *A bit of both.*
>
> ***Carole:*** *Would you have preferred it if the doctor had talked to you?*
>
> ***Harry:*** *Yeah. (Harry, YP)*

For Harry, the fact that his mum was informed about his fertility before him, proved difficult and "awkward", and he did not go on to bank any sperm. An interesting article by Shnorhavorian et al (2011) discusses how boys become more private as they enter different development stage in their early to mid teens. This stage may attract acute discomfort when discussing fertility in the presence of parents, and their immediate reaction to being asked about banking of sperm may be a firm "no". Parents might, at this point, express contrasting concerns for the young person's long term interests and future parenthood. Shnorhavorian and colleagues, then, advocate a better appreciation of family dynamics and consideration of the young person's immediate wishes with their long term interests, so as not to close off all discussion. This is a pragmatic process, as evidence suggests that many young people do not think about parenthood until either later in life, or when they meet a potential long term partner (Crawshaw & Sloper; Zebrack et al 2004).

Discussing fertility in the presence of other family members is not always problematic. Both Kieran and James were involved in discussions about fertility with their consultants as a family, i.e., with their parents present. Kieran, at 13, along with his mother, recall being informed by a consultant that he was too young to bank any sperm. James, however was considered biologically developed enough to bank sperm, and was the only young person that did this. For James and his family, the fertility discussion worked well. Nevertheless, James' father, William, did find it "strange" discussing his son's fertility, and also had serious reservations about future cost implications for storing his son's sperm. Currently, storage is set at 10 years, which is problematic for TYA's. As boys are able to bank sperm as young as 12, this means that by age 22 they need to have made a decision about either starting a family, or negotiating further storage terms.

The two girls in this younger sample each had very different experiences around their fertility. Zoe's doctor had an in-depth discussion with her, on her own, and was informed of the possible implications that different types of treatment would have on her fertility. Zoe received a very high standard of information about her fertility options and incorporated this when making decisions around the type of treatment she opted for.

In Rebecca's case, the issue of fertility did not arise until she overheard other young people discussing the side effects of treatment on the TYA unit. Although this initially upset Rebecca, she was proactive and sought out her consultant to find out how and whether her diagnosis and treatment would affect her future fertility. Her consultant reassured her that that her chemotherapy treatment should not affect her fertility. When Rebecca was asked if she would know where to seek future advice about the status of her fertility, however, she was uncertain of how to go about this. This uncertainty around the processes required to confirm fertility status can influence young people's beliefs and behaviour around contraception, and concurs with findings from a UK study on young people, cancer and fertility (Crawshaw and Sloper 2006).

It is important to note that inconsistencies in fertility information for young people aged 12 to 15 years, is not simply down to an 'ad-hoc' approach. Rather, it can be located more helpfully in a framework relating to age. This particular age range encompasses a range of pubertal stages, ranging from pre to post –pubescent, which, especially in the case of boys, impacts on the ability to produce and preserve sperm. Added to this are the types of cancer young people have, which can also influence preservation. Another factor is that many young people at age 13 are beginning the transition towards independence, and developing a sense of self, which includes their sexuality. As in the case of Harry, issues around sexuality and reproduction often become private matters, which need to be dealt with in a sensitive and considered manner. Discussions around reproduction should therefore take into consideration family dynamics, as well as where the young person is positioned in the family, and the relationship between the young person and other family members. However, these factors may not always be obvious, and broaching fertility will always be an area where the complexities and family dynamics must be judged on a case-by-case basis (Crawshaw & Sloper 2006; Shnorhavorian et al 2011; Whelan 2003).

Young Adults

The table below is similar to the younger teenagers' table, and shows how fertility information was received, and by whom.

Table 1

Name	Age at Diag.	Level of Fertility Info Rcvd	Who informed Young Person	Preservation Offered
Michael	22	High	TYA Consultant	Yes
Joe	19	High	TYA Consultant	Yes
Jordan	18	High	TYA Consultant	Yes
Matthew	24	High	TYA Consultant	Yes
Ryan	19	High	TYA Consultant	Yes
Gemma	18	Low	Adult Gynaecology	No
Natasha	18	Medium	Adult Head & Neck	No
Poppy	20	Low	Adult Head & Neck	No
Kate- Parent of Daughter	22	High	Adult Gynaecology	No

Fertility information for young adult men in this sample was excellent, with all receiving a high level of information and counselling around their fertility, and all banking sperm. Important to note, is that all six young men had been referred directly into the TYA service.

Whilst information for young men was very good, three of the four young women in this sample did not feel they enjoyed similar standards. Notable again, is that none of the young women's first point of contact was with the TYA Service. Rather they were with other regional hospitals, or other adult cancer site specialisms. In addition, none of the young women had undergone any fertility preservation.

Natasha had been given some information around fertility, and informed that treatment may decrease her fertility options. Her father had pressed for information about egg preservation:

> *I knew at the time that, like, that boys could store their sperm or something, because my dad said this "well why can't the females store their eggs?" And they said to us "It's not available" and that was one of my dad's biggest issues. (Natasha, YP)*

Natasha remembered only that they were told egg preservation was not available, but they were given no explanations as to why. Natasha was also unaware of her current fertility status, and when asked whether she knew where to go for advice and information on her future fertility, she was unsure about this, and assumed that she would visit her doctor. She also felt quite strongly that the information she received about her fertility was poor, and needed addressing.

Gemma and Poppy also felt the information they received about their fertility was inadequate, which resulted in additional distress for Gemma:

> *They explained that I'd never have my own children but that was it really! (Gemma, YP)*

Gemma's mother also took part in the evaluation, and was asked the same question on fertility:

> *I did ask [Name] when we were first told she was to have the hysterectomy, I did ask if any eggs could be saved and he said: "No!" No explanation as to why, and because we were in the state we were in we didn't think to ask why. So, I don't know, apart from that, he just said she would never have her own family. (Jennifer, Parent)*

Gemma and her mother both felt the fertility information they received was conveyed in an insensitive manner, which caused distress. Worth highlighting, in Gemma's case, is the use of the terms "your own family", and "your own children". What is implied here, is that conception for Gemma will not be possible after surgery. The emphasis on "your own", makes visible the biological terms in which 'family' is conventionally understood. There are, of course, other options open to Gemma, such as surrogacy and adoption. However, the language used to inform Gemma about her decreased fertility, also reinforces young people's reservations and reluctance to pursue non-biological parenthood (Crawshaw & Sloper 2006; Zebrack et al 2004).

Poppy's situation was more complex. She recalls that no information was given to her about fertility until she, herself, brought up the subject after completion of her first treatment. Poppy also felt that information was withheld from her regarding the implications of a further type of treatment that would decrease her fertility options significantly:

> *But this four week treatment that I was going to have, they didn't tell me that if you go for that you could lose all of your fertility, which I didn't think that was right! I know they wanted me to be better, but I didn't feel that-I should, I should be making that decision! "Hang on a minute, I want kids and if I have that, I won't have kids at all!" So I refused it. (Poppy, YP)*

Poppy liaised closely with her specialist nurse to negotiate a scan to ascertain whether the cancer had gone. Poppy was told the cancer had gone, but the second bout of treatment would further decrease the risk of return. Poppy then went to another local hospital to assess her fertility status, and found she was still fertile. After thinking through the advantages and disadvantages, Poppy decided not to have the second treatment so as to preserve her fertility.

A more positive experience was reported by Kate, whose daughter was 21 when she was diagnosed with cancer and referred to the gynaecology department at Leeds. Kate recalled that her and her daughter received a high standard of information. Although Kate's daughter could not preserve any eggs, they were given explanations as to why, and also knew where to go, and whom to contact, should she want to determine her fertility status in the future.

Fertility constitutes an important factor in the lives of all people; both decisions to reproduce and *not* to reproduce, and is a subject that must be broached in a sensitive and informative manner. Some of the young women in this sample did not receive as much information as they required, especially around why their eggs could not be preserved, the status of their fertility, and where to go for future information and advice. That these women's first point of contact was with specialist departments other than the TYA service, has wider implications for adult women. Part of the problem may lie in the unfamiliarity and lack of experience that adult specialists have with young women. Nonetheless, studies around infertility highlight it as upsetting and, in the case of some, increased psychological problems such as anxiety and depression can arise (Crawshaw & Sloper 2006: NICE 2012; Zebrack et al 2004). Equally important is that uncertainty about fertility status can influence behaviour around contraception. In particular, when young people believe, or suspect their fertility has been reduced, this can result in decreased contraception use, leading to risks of unplanned pregnancies, and/or sexually transmitted infections (Crawshaw & Sloper 2006, Zebrack 2004).

Finishing Treatment

Finishing treatment and recovery is a process, rather than an event and brings with it a wide range of emotions (Harvey 2004). It can bring relief and a sense of freedom and reassurance when the support of staff is no longer needed. On the other hand the same can bring about feelings of insecurity and isolation (ibid). Moreover, there may be feelings of pressure to return to the same states of being that were familiar before the cancer was diagnosed. Emotional stress, then, is common, however, this can consume the energy needed to recovery (ibid). In this evaluation there were mixed responses to finishing treatment. Some young people expressed relief and happiness, whilst other young people, along with the majority of carers, experienced anxieties and insecurity.

For young people who had a relatively worry-free time finishing treatment, this tended to be connected to the information they received about managing their continuing health needs and symptoms, and in particular, the high levels of support available from their specialist nurse, and other allied health professionals:

> *Yeah, I got stuff that carried on saying what to look out for, and still coming to clinic every week for a bit after, and got all my check-ups and stuff, but yeah, I got a lot of help. (Joe, YP)*

The Leeds Service excels in its specialist nurse support, and when advice can be obtained easily this clearly assists young people in the transition from regimented treatment to longer periods between appointments that define 'follow-up' or 'follow-on' treatment.

Not all young people had an easy transition when finishing treatment, though, and three young women discussed their problems. Both Natasha and Zoe were treated at the younger TYA Unit, and thought the information they received was vague. Natasha remembered that information only told her when her follow-up appointments were, however she was particularly concerned about which foods she could resume eating, and whether she could return to drinking ordinary water. Zoe described finishing treatment as a difficult period:

> *I think people will agree with me when I say this, coming off treatment is really hard, and no one was really there. You're kind of like, your safety net is taken away, it's just... it's really hard finishing. ... Just coming off treatment and what to expect, and life after treatment. Because you kind of live your life like, with a massive life threatening illness, and then when you've stopped and your treatment has stopped. You're like 'wow!' And you kind of need a bit of help and support when it's not there. (Zoe, YP)*

Entering a different stage in the cancer journey can sometimes feel like an abrupt change, and Zoe would have benefited from practical, and emotional support, especially around what to expect. Similarly, Poppy, who had recently finished treatment and was treated on the older TYA unit, felt more information could have been available to her:

> *I've not got anything, like the symptoms to look out for, because I did have a bit of a scare, recently, but I didn't look out for it, I just noticed it myself. So they didn't say to me: "look out for this, this and this." (Poppy, YP)*

The TYA service do now provide a monthly 'moving-on' support group for young people finishing their treatment, which is held in Leeds. The 'moving-on' group is led by young people and should help to alleviate the anxieties of finishing treatment.

Finishing treatment was particularly difficult for all six parents interviewed. There were a number of reasons for this, some parents felt they needed more information around finishing treatment but, primarily, parents were worried that their child's cancer would return:

> *Finishing treatment is horrendous! ... [W]hen they're having treatment it's under control, it's all being killed ... But when they stop treatment, it could all come back, that's what you think. And it might do! And it's the worst time ever because every little thing you think it's cancer. (Kate, parent)*

Kate's extract was typical of how parents felt when their child, whatever their age, finished treatment. Feelings of relief are common, but these feelings are combated, somewhat, through feelings of insecurity, anxiety, and fear. Connected to this was that parents perceived the special, and intense care their child had received had ended quite suddenly. This was despite the support that remained available to parents from ward staff, and specialist nurses:

> *Even now, I think one of the big things is when you go home after it all, you've still got contact here, I mean you can ring them up ... 24 hours a day. You can just ring the ward up and someone will talk to you, just to take that you know, 'concern' away. (William, Parent)*

Finishing treatment, then, can be difficult for all concerned. Parents, especially, struggled with the sense that clinical support has been withdrawn, and fear around the cancer returning This can bring about emotional insecurities, which may impact on the emotional environment they provide to recuperating TYA's. However, these emotionally difficult experiences can be, and clearly are, mitigated by drawing on the supportive relationships established during treatment on the ward.

Recommendations

1. Provide appropriate 'information' and 'support' web site links for young people.
2. Uniform guidelines to be developed around providing fertility information young people.
3. Fertility information to be given as standard, whether or not diagnosis or treatment is expected to cause difficulties.
4. Fertility information to continue to be given as standard when young adults referred from other adult departments, or hospitals.
5. Clear information on where young people can seek future information and advice regarding the status of their fertility.
6. A comprehensive end of treatment review, and plan to be given to all young people. To include: diagnosis and treatment summaries, late effects; timing and content of follow up visits; symptom checks; prevention advice; dietary advice; information about individual and group support; sexual relationship advice; drugs and alcohol advice; legal rights around employment and insurance; acknowledgement that finishing treatment can be emotionally hard for some people, with an indication of some of the possible feelings.

MULTIDISCIPLINARY TEAM WORKING

CONTEXT

An integral feature of the TYA service at Leeds is a comprehensive Multidisciplinary team (MDT), which has the aims of improving outcomes, and ensuring that appropriate clinical staff and allied health professionals are identified and contribute to age appropriate care for young people with cancer. A multidisciplinary team in the context of TYA care can be defined as:

> *A group of health care and social care professionals who provide different services for patients in a coordinated way. Members of the team may vary and will depend on the patient's needs and the condition or disease being treated" (*http://www.encyclo.co.uk/define/multidisciplinary*).*

As cancer occurs within a complex of psychological and social factors, there are a number of allied health professionals on the TYA unit providing a network of psychosocial support. These include CNS's, a learning mentor, social workers, YSC's, psychologists, a dietician, and a complementary therapist. Severe and acute stress usually accompany diagnoses of cancer (Maunsell et al 1992; McBride et al 2000), which, if not addressed, can contribute to emotional distress and a lower quality of life (Anderson 2002). The TYA support workers, therefore, provide a wide range of psychosocial services designed to enhance the TYA service as a whole. This section discusses these services and evaluates them from the perspectives of young people, and their family and carers.

KEY-WORKERS

In recent years, a number of strategies, policies and guidance have been developed to shape cancer services for children and young people. One common aspect to these policies are the development of Key-workers, who coordinate care across the system at each stage; assess TYA psychosocial support needs, facilitate and sign-post for these needs; and provide support for individuals and their families throughout their cancer experience. The Leeds service has provided this type of comprehensive support for a number of years, and the role tends to fall within the remit of a CNS, but it can also be filled by other individual members of the TYA staff, as well as being a team effort.

Participants were asked about their experience of having someone who supported them throughout the their cancer experience. All participants reported that they knew who to speak to if there was something about their treatment or illness they did not understand, and tended to name the person with whom they had formed a trusting relationship, and whom they contacted if they required information. The older TYA's and their families and carers, tended to name their CNS, of whom they were highly appreciative:

> *Available 24 hours a day probably, seven days a week! She's the most amazing person, and that isn't just for [daughter] that is for me! She's the most wonderful person ever and I probably couldn't have managed without her! (Kate, Parent)*

> *[Name]. She was really good, really good. Normally I was there with-the two of us were there together with her, but she did draw me aside a couple of times to say 'if you need any support as a carer then get in touch'. (Stephanie, Partner)*

> *Yeah [Name] did that, and she would like text, and she'd come to oncology appointments and still does now. She's really nice and we get along ... And she understands as well. And like when I was on the ward she'd come and chat with me and like sat with me while I was having my chemo, and just talked about normal things.(Gemma, YP)*

For young people and their carers, the CNS had a wide remit, and provided information about diagnosis and treatment, accompanied TYA's on appointments, acted as mediator between consultants and young people, and translated clinical information in a more TYA-friendly manner. They also provided much needed emotional support to families and young adult partners, and also provide reassurance and companionship to young people.

Naming the Key-Worker

Although all participants were aware of whom they could speak to regarding any information they required, a significant number of participants, were unaware of whether or not they had actually been allocated a key-worker, and often did not know what a key-worker's role was.

Two of the eight young people aged 18 and over were unsure of who their key-worker was. However, at the same time, they were able to name their CNS as their main point of contact. Teenagers and their carers on the paediatric side of the service were less likely to know who their named key-worker was. When participants were asked whether they were allocated a key-worker, or liaison person, who would stay with them from start to finish, most did not know who this was and tended to name a social worker, consultant or Macmillan nurse:

Factors that might Influence the confusion around key-workers and their roles includes the cognitive developmental stage of the younger participants, and their capacity for understanding and retaining information. Another factor rests with the different working practices that operate between the 13-18 TYA service, and the 18-25 service. Although these differences are subtle, the younger side of the service has developed within a paediatric philosophy of care, and key-workers there tend to be specialist Macmillan nurses, who also often take on a range of other roles, such as education liaison, and community care coordination. What these findings suggest, is that the key-worker role is not as clearly defined as it perhaps could be. However, the findings also suggest that any member of the TYA team can act as a key-worker, or main point of liaison, and this appears to work just as well.

Not having a named key-worker, and instead working as a team, can be beneficial. Team working ensures young people and their families do not feel isolated when the named key-worker is away from work or on leave. Having a number of staff available at the end of a ward phone is a valuable asset, however, it is unlikely that each member of staff will have complete knowledge of the psychosocial needs of the young people and their families. A key-worker would have knowledge of the historical and psychosocial history of a young person and their family, and not having to repeat aspects of this information to ward staff may alleviate some of the emotional stresses on families. At another level, however, different working practices may confuse teenagers in their transition to young adult services, and developing continuity in working practices could aid more successful transition outcomes.

Recommendations

1. Information pack to be given out at diagnosis, outlining what the service provides, with names and contacts for the different psychosocial support available.

EDUCATION AND THE LEARNING MENTOR

A diagnosis of cancer in young people often occurs at a crucial stage in their education. Interruptions caused by cancer diagnoses and treatment can jeopardise not only their ability to finish their education, but also their future employment prospects, and becoming and/or remaining independent. However, when age appropriate educational needs are provided for, there is evidence that this contributes to improved outcomes for young people (Palmer et al 2007; Payne et al 2011; Smith 2004; Wilkinson 2003; Whiteson 2003). In the UK, local education authorities (LEA) have a duty of care to maintain young people's schooling whilst they are still in compulsory education. As such, they provide a mix of home tuition, as well as educational facilities within health services. Leeds Teaching hospitals, therefore, have in-house tuition for children and young people up to the age of 16. On the other hand, educational support and facilities are rarely provided as standard for TYA's over the age of 16, and it is rare for adult wards to provide any support. To compensate for this, the Leeds TYA service provides a learning mentor.

Compulsory Education

All except one of the participants, aged 16 and under at the time of diagnosis were happy with their educational support, and reported positive experiences:

> ***Carole:*** *And did you keep up with your school work?*
>
> ***Zoe:*** *Quite well actually, I was told I would get no GCSE's and when I got them, I got 6 or 7! (Zoe, YP)*

For this age cohort, their continued education whilst in hospital comprised a mix of support not only from in-house hospital tuition, and home schooling, but also from youth/activity workers; learning mentors, key-workers and specialist nurses. The common factor between this age group was that the majority were supported by their specialist Macmillan nurse in the form of liaison with schools.

Other educational support for young people came from YSC's. Rebecca was 14 when she was diagnosed with cancer, and discussed how she received hospital tuition, but also how the side effects she was experiencing at that time made it difficult to write. Rebecca's youth co-ordinator enabled her learning by obtaining a laptop for her:

> *I was like really shaky so I couldn't write, I was like that, trying to write and then my writing just looked like a scribble, so I used the computer to do work. (Rebecca, YP)*

Rebecca went on to say that she also had work sent from her school to complete, both at home as well as in hospital. However at certain stages in her treatment, fatigue meant completing the work became difficult:

> *[YSC] realised it was too much for me to do, so he had a meeting with the school and said' could we... you know the situation, could we... is there any chance she can look at doing the most important ones?' (Rebecca, YP)*

The relationship established between Rebecca and the YSC enabled him to recognise the points at which she struggled to keep up with her studies. He then took up the role of learning mentor, mediated with Rebecca's school, and negotiated a decreased work-load. This encouraged her to continue her schooling.

Although educational support was very good, indeed, there was an element of confusion around who exactly the 'learning mentor' was, and the role they performed. For example, LEA's would organise home tuition, and participants often confused this with the learning mentor. Confusion around the term was not restricted to young people themselves, who might not be expected to understand the concept, rather, it does not appear to be fully understood by parents either. It may be that a specific learning mentor was involved in, or initiated some of the educational arrangements that participants talked about, and parents and young people were unaware of it. When learning mentors were mentioned, participants made sense of this by categorising anything concerned with education as 'learning mentor', which included the whole range of educational support mentioned above.

Confusion around the learning mentor role, however, is not necessarily problematic. Clearly, educational advocacy can be, and is taken up by other members of the TYA team. In one sense this is advantageous, as team-working practices help to avoid problems associated with absence. However, these forms of team-working practices can mean young people and their families can ocassionally be overlooked. Indeed, what follows next is an example of what can happen when families are unaware of the support available from learning mentors.

Negative Experiences in Compulsory Education

Reintegration into school life, and acceptance by healthy peers is crucial to the continuing education for TYA's, however this can sometimes prove challenging for the young person, family and education staff (Koch 2004). One young person in this sample experienced negative incidents on return to school:

> *I'd been into school, and I said 'look, you know, he's going to be wearing his hat, he's got no hair', he won't tell anybody so please will you listen to me?' I wrote them about three letters and regardless, stupid things, the Health woman and the Health and Welfare lady at school that goes round and makes sure that people... I mean she was told that Kieran was in school when he was ill and he had no hair ... and then she didn't do anything, and in his dinner hour she walked up behind Kieran and shouted "No hats in school!" and pulled his hat off, so about 300 kids all saw his head!. ... The PE teacher, had him stood out for the full hour in sunshine when he was only-he actually said to his teacher "I don't think I should be out here", and it was like "shut up Kieran, just because you don't want to field!" (Lauren, Parent)*

Lauren's son, Kieran, was 13 when he was diagnosed with cancer. In this instance, his key worker had liaised with the school, but communication difficulties had subsequently occurred. What stands out here, is how Lauren had repeatedly attempted to liaise with school herself. She had been proactive and established communication with the school's welfare officer, informing her of Kieran's imminent return, his side effects, and the specific support he would require during the school day. Unfortunately, it appeared that information was not shared with appropriate members of staff, and Kieran's return to school proved to be distressful for both him and his mother.

A diagnosis of cancer is also stressful for the young person's family and significant others, with the period following the end of treatment being particularly difficult. As the above extract shows, Kieran's mother was placed under great stress. In addition to caring for Kieran and her other younger children, she also had to undertake further work through school visits and letter writing. One feature of the learning mentor's role is to mediate in the return-to-school for young people. In this example, Lauren was unaware of a specific learning mentor role, as she assumed school liaison was carried out as part of the Macmillan nurse's role. It is important, therefore, to ensure that all TYA's and their families and carers are aware of the learning mentor and how this person can assist them.

Further and Higher Education

Young people in this sample received a mixed level of educational support. Of the eight young people diagnosed with cancer at age 18 and over, two were in further education and two were in higher education. Of these, one young person, Gemma, was in further education at the time of her diagnosis, and decided to leave college whilst undergoing treatment, but returned the year after. Gemma already had a good relationship with her college tutors and liaised with them herself, thus she did not need a learning mentor.

The three remaining young people in further/higher education did make use of the learning mentor, but had mixed feelings around communications. Michael, for example, was in his last year at university, and initially struggled to identify the learning mentor. A diagnosis of cancer, coupled with the wealth of information that accompanies it, can amount to information overload. Thus, for many young people and their families, further sign-posting to the learning mentor from other members of staff is useful. Indeed, once Michael realised who his learning mentor was, he found her very helpful and supportive:

> *She sorted it out and she wrote all the letters and I didn't have to do anything which was quite nice really. (Michael YP)*

Ryan was also supported by the learning mentor, but was unsure whether communications had actually been carried out:

> *Yeah I think she... she was going to get in touch with college for me, I think she did actually, just to... because I had a few deadlines that I couldn't keep up. But yeah she said she'd ring up for me,*

> *I don’t know if she did in the end.(Ryan YP)*

Ryan’s uncertainty was also experienced by Natasha, who was studying at university when she was diagnosed. Like Ryan, Natasha was supported by the learning mentor, but she was also unsure whether communications between the learning mentor and her university had been completed. Both Ryan and Natasha required confirmation and/or feedback regarding liaisons with their education facility.

Natasha was also a young adult on the paediatric side of the service. As an outpatient here, she felt that lack of space was not conducive for studying. When asked what changes she would make to the service, she responded:

> *When I was having treatment there was nowhere for you to study whilst I was having that treatment. You might not feel well enough, but I think if there is that possibility then you can do. I do know one day I brought some work in to try and do, and the nurses were like “we’ll try keep people out of the room and keep it quiet” but it never happened, everyone keeps coming in and asking you for this and asking you for that, so that’s the only thing. And for them to liaise a bit more with the University.(Natasha YP)*

For Natasha, the shortage of outpatient space created difficulties in terms of private or single treatment rooms, and this had an adverse impact on her. People study in different ways, but for those who need quiet, peaceful surroundings, and feel well enough to study, there was no appropriate place for them to do this. As some outpatient treatments can be prolonged and intense, the lack of appropriate study facilities may put some young people at a disadvantage.

Recommendations

1. Named learning mentor, complete with contact number, and a synopsis of their role to be included in initial information pack.
2. Learning mentors to be allocated to young people through a formal system. This would ensure mentors themselves had a detailed list of young people, allowing them to make regular checks on any support needed and/or already provided.
3. Teenage Cancer Trust Education and Awareness Team to visit schools and provide information and advice around TYA cancers – with permission from the young person.
4. To provide written confirmation to young people in further and higher education detailing all communications with the education facility, including copies of any written correspondence, outcomes and decisions.

SOCIAL WORKERS

There are three part-time social workers at the Leeds TYA units, who are funded through Leeds City Council and the charity Clic Sargent. Social workers were highly valued by all participants, particularly in relation to their financial assistance and expertise:

> *Took a lot of the financial worry out of things. (Cameron, Parent)*
>
> *Yeah she was lovely. She told me what I was entitled to, because I’d stopped working. So she was like you’re entitled to this, this, this and this. And then she told me about the Sargent clan or something like that (Poppy, YP)*

Young people with cancer often have to take unpaid leave from work. In addition, carers usually experience some form of decrease in income, whether due to incremental decreases in sick pay, unpaid leave, having to lower working hours, or leaving work completely. Added to this, young people and carers may incur extra travel costs, child-care costs, and food and utility costs. For all participants, social workers assisted in completing forms associated with grants. In particular, the one-off non-means tested grant of £170.00 offered by the Clic Sargent charity to all families with a young person aged 24 or under. Having allied health professionals within the service who are able to give benefits advice, and assist with benefit claims forms, clearly alleviated some of the financial stress associated with illness and caring.

In a number of cases social workers also helped with employment difficulties, as William reports:

> *My wife's work. We had a bit of trouble because they were being a bit funny with work - my wife having time off, and she assisted us loads with that. So just some nicely worded documents, and one thing or another, that if I'd had done them they wouldn't be nicely worded. It's not something I'd ever say I would use first off, but she was very good. (William, Parent)*

The status of social worker also carries a professional discourse and level of authority that is not available to the 'ordinary employee'. As with the benefits system, social workers were able to enter into and navigate other professional systems with relative ease which, again, helped to alleviate financial and emotional stress.

Also worth highlighting, is that more than half of participants did not recognise social workers as 'social workers':

> ***Carole:*** *Did you see the social worker?*
>
> ***Michael:*** *social... who is the social worker?*
>
> ***Carole:*** *That would have been [Name].*
>
> ***Michael:*** *Oh the CLIC Sargent person? (Michael, YP)*

Reasons for this may be that social worker posts are part-funded by Clic Sargent, and that might be how they introduced themselves. But as responses show, social workers were also directly associated as people who provided benefits advice and financial and employment assistance; roles for which, arguably, they are not best known.

There was only one problem reported by participants concerning social workers, which came from the parent of a 13 year old boy diagnosed with cancer. The family were assigned a social worker, with whom they formed a positive relationship, and who helped them to claim Disability Living Allowance. However, the social worker left soon after, and although a new social worker was assigned to the family, contact was sparse and a new relationship was not established. It is possible that this family was overlooked, during the changeover of staff, which was unfortunate as the family also experienced a number of social problems, both at home and at school, and may have benefited from the wider support that social workers would have provided.

Recommendations

1. Social workers to be utilised to their full potential and capacity, that is beyond benefits and financial advisors.
2. Formal referral system to be developed for allocating social workers to young people and their carers.

YOUTH SUPPORT CO-ORDINATORS

Cognitive and intellectual development forms a major feature of transitioning from childhood to adulthood, along with social, sexual, cultural, and identity development. When a young person is diagnosed with cancer, these important developmental and social skills can be disrupted. To help combat this disruption, YSC's are employed as a key component in the package of psychosocial support. They work hard to provide a sense of normality, and help to maintain social networks for young people, provide distraction during treatment, and facilitate support groups after treatment has finished.

The majority of participants, together with a significant number of staff, were very positive and appreciative of YSC's:

> *The activity co-ordinator, she's probably the most important person on the ward, and the difference when she's not here is amazing.... If [Name] not here there's nothing to really get up for and they'll just stay in bed with the curtains shut. (Staff)*

> *Yeah at the time there was [Name] and [Name] and they were fantastic. [Name], he used to come and sit on [ward] with me and teach me how to play guitar, even though I failed miserably! But he was, they were fantastic, both of them, and [Name] the same, she's fantastic you know, any problems just give them an email or ring or whatever, if you're feeling down they'll try and cheer you up. It was ace, so fantastic at their job! (Jordan, Young Person)*

Staff members felt YSC's were invaluable team members, and the majority of young people welcomed the distractions that YSC's brought to their day. YSC's also helped elevate the moods of young people, which helped them through their treatment. This was reiterated by Poppy, who had struggled emotionally and psychologically:

> *They called the psychiatrist to come and speak to me and then [Name], I think she's like a worker on that ward, she was lovely, she kept coming in every day, because I was there for five days every two weeks, just to see how I was and like if I wanted anything, because I had to be on my own in that room, I couldn't go out and enjoy the activities so she used to bring me the activities and bring someone to speak to me (Poppy, YP)*

The remit of YSC's is wide, and they also contributed to the varied network of educational support:

> *Well he'd pretend to be asleep if the teacher walked in, but if [Name] came up to him he would sit and have a drink with him, have something to eat, talk about stuff and then within ten minutes they were doing all sorts, computer was out, the screen was on … and you need that and he came down to his level which was really, really, good. (William, Parent)*

What may also be important for the younger TYA's is the gender of the YSC. Hospital wards, and health services in general, are predominantly female environments. Without taking anything away from the excellent service that women provide as health and allied health professionals, the young men in this sample were particularly enthusiastic towards the male YSC. As William, above, points out, his son established a positive relationship with the YSC, to the extent that he not only agreed to keep up with his studies, he actually enjoyed the process. It may be that different sexes bring different qualities and skills to the role of YSC. Having support staff of different sexes available during young men's time on the unit may help in a number of ways, such as talking through emotional, social and sexual issues.

YSC's also provided support to significant others:

> *Youth worker [Name] fantastic! Tries to get you into things, has been a big support for me. Again when [Daughter's] been down having-she was having an operation, I went up there, she got me making cups and everything! Because I was in a right state! Very, very, supportive to families. (Kate, Parent)*

For this parent, the YSC helped to relieve the anxieties that are characteristic whilst loved ones are in surgery. Stephanie, the partner of Michael also discussed the role of the YSC:

> *The ward itself was, I don't know, obviously it's a place for treatment, obviously it's not an overwhelming positive attitude, but they worked very hard to make it kind of a happy environment. It was always quite busy, there was activities available, people like [Name] I don't know what her job title is, but she made it really kind of social in a way. She was lively and good to talk to, good for the patients and for the visitors. (Stephanie, Partner)*

YSC's constituted an invaluable feature of the service. They provided a sense of normality, and were beneficial to patients, carers, visitors, and staff. They helped facilitate group support, information sharing, and coping strategies. They also helped motivate young people, offered emotional support, provided a social atmosphere, and organised social outings for young people, which continued after treatment had finished. Indeed, maintaining contact with young people after treatment can be especially useful to young people, who can feel isolated and lost whilst transitioning into this stage of their cancer journey.

Recommendations

This was an area that needed little improvement.

PSYCHOLOGICAL SUPPORT

It is common for TYA's to have low moods, mood swings, and to be uncommunicative. It is also common for young people to experience difficulties in discussing their feelings and emotions. Young people diagnosed with cancer may, understandably, have low moods, which can be seen as a 'normal' and realistic reaction. The Young Minds charity cites physical illness in young people as one of the possible triggers for affecting mental health. However, identifying the symptoms associated with anxiety and depression could be difficult.

The Leeds TYA Cancer Service provides specialist, age appropriate psychological support, which, in general, worked well. However, annual leave, sickness, and maternity leave, could occasionally lead to a lack of resources for younger TYA's.

TYA responses to psychological support were complex. Some of the younger teenagers were unaware of psychologists and the role they played, or the support they could offer:

> ***Carole:*** *Did you use the psychologist at all?*
>
> ***James:*** *What's that?*
>
> ***Carole:*** *Psychologists, it's if you're worried about something and you want to talk about something that you might not want to talk to your mum and dad about, or you might not want to talk to the doctor about, then you might go and speak to a psychologist.*
>
> ***James:*** *No, I don't really have anything that I want to talk about! (YP)*

James was fifteen at the time of interview, and appeared resistant to the idea of psychological support. There is a stigma attached to psychological and mental illness, and many younger teenagers may not have developed the cognitive skills, or the life experience to understand how physical illness can affect mental health. As talking therapy is not something that is familiar to many people, and especially young people, the concept of talking through an emotional problem, with a view to this process being helpful, or bringing about possible solutions or coping strategies, can be alien. As a result, more than half of young people interviewed did not use the psychological support services, and had mixed feelings about how useful it would have been. For example, neither Matthew nor Michael had seen a psychologist, but they also felt they were not the kind of people that spoke to others about "*personal stuff*". Rather the conversations of these young men with others, including friends and professionals, tended to consist of general chit-chat.

Jordan was 21 at the time of interview, and considered whether he might need to talk to someone, but would not be sure of how to go about initiating this process. He appeared confused as to whether psychological support would be helpful.

> ***Carole:*** *And did you come into contact with the psychologist at any time?*
>
> ***Jordan:*** *No, not really. I don't think I need them, I maybe do now but...!*
>
> ***Carole:*** *Well you know if you do now, there is one that you can access here.*
>
> ***Jordan:*** *Yeah, yeah, I think they did say that if I was struggling mentally with it then they had somebody for me to be able to go and see if I wanted to, but I don't know who that was because I didn't really look into ... I didn't ever require it, if that makes sense? (Jordan, YP)*

In all, six young people had seen a psychologist, two younger TYA's and four older TYA's. Of the younger TYA's, Zoe, felt it had helped, however for Harry, the few sessions he had with the psychologist felt strange:

> *Didn't really enjoy it ... felt a bit weird" (Harry, YP)*

Of the young adults, Poppy and Ryan felt psychological support had helped. However, Gemma, like Matthew and Michael, felt she wasn't suited to it:

> **Carole:** *What was your experience like with the psychologist?*
>
> **Gemma:** *It wasn't really me to be honest! But it helped, and she was really nice and I've still got her number, and she said if there was anything I ever want to ask about, to just phone in and I can go back.*
>
> **Carole:** *When you say 'it's not really me' what do you mean by that?*
>
> **Gemma:** *I don't know, I just… I think I'd rather just get on with things instead of talking about it and sitting and going through everything.*

For Gemma, although she considered her psychological support helpful, her experience with the psychologist was uncomfortable, and, on balance, felt she would rather "*just get on with things*". The same was true for Joe, who was also ambivalent regarding how helpful his sessions had been:

> **Joe:** *Yeah I think I saw her once or twice, I can't remember what she was called, but yeah, I've seen her once or twice.*
>
> **Carole:** *Was that helpful?*
>
> **Joe:** *It was, and it wasn't. I don't know, it might have been me and I didn't sometimes like talking to people. It did help, obviously, but I don't know . (Joe, YP)*

It is interesting that, overall, only three TYA's reported positive experiences with psychological support. However, this does not appear to be down to the psychological service itself. Rather, there was a common thread running through young people's accounts that points to the optimum way for dealing with cancer as, to 'just get on with it'. Also common was that discussing emotional issues was unfamiliar and uncomfortable, which may have had a direct bearing on young people's resistance and ambivalence towards psychological support. It may also be that the older the person, the more open they became to physical illness affecting mental health. Indeed, this was borne out with half of parents and partners who were interviewed, where one parent had accessed the TYA psychological support service, and another three had visited their GP to seek advice on their mental health.

In short, evaluating the area of psychological support was not straightforward, and analysis of participant responses were complex. Nevertheless, what can be said, is that a number of TYA's struggled with mental health issues, but only half accessed psychological support, and only half of these were satisfied with the support they received. If young people are uncomfortable discussing personal and emotional issues, then mental health problems can be considerably difficult to identify. The most reliable source of information concerning psychological distress, though, is the patient, and at the time of evaluation, the Leeds service were trialling an adapted version of the psychological distress questionnaire at key stages of young people's cancer.

There is a clear need for further research into this area, and the possibility of a psychosocial screening tool should also be taken into consideration. Other sections in this evaluation report on how young people felt isolated when treatment stopped, and a number also struggled with problems around bereavement related to peer deaths, fertility, social relationships, self image, and financial debt, which can all contribute to, and create, anxiety, depression and other negative emotional states. These psychosocial stressors are also usually dependent on the life stage of the young person. The team at Leeds are highly developed, and ideally placed for bringing these different areas together, and supporting TYA's in a more holistic way.

Recommendations

1. Review how formal psychosocial screening is carried out throughout the cancer journey.
2. Introduce psychosocial screening/assessment tool to identify different areas of needs.
3. Consider naming 'psychological support' as something less loaded with meaning, and thus more acceptable.

CARER HEALTH AND SUPPORT

Carers and significant others play a vital role in actively shaping the experience of people with illness, and, in turn, also share in this experience in practical, emotional and social terms (Thomas et al 2002). It is now widely acknowledged that informal carers have their own psychosocial needs, as set out by the Department of Health's (DoH) *NHS Cancer Plan* (2000), and in the influential Calman-Hine Report (DoH 1995):

> *The development of cancer services should be patient centred and should take account of patients', families' and carers' views and preferences as well as those of professionals involved in cancer care. Individuals' perceptions of their needs may differ from those of the professional (DoH 1995, p6).*

The ability to cope with the extra responsibilities of informal care is dependent on carers' own state of physical and mental health, and on their material, and relational social circumstances. Thus, the needs of carers are as multidimensional as the patients, and will vary at different stages of the cancer journey. Recognising and meeting these needs in a political and economic climate that continues to seek cost savings in 'non-essential' frontline interventions and services is not an easy task (Boudioni et al 2000, Mitchel, 2007). Nevertheless, research suggests that carers need information about the disease and its treatment, practical knowledge and skills to care for medical needs, emotional support, support to care for their own physical health, and social support to help with financial needs, employment, and other caring responsibilities (Soothill et al 2003).

Practical Support

In terms of medical support, all carers were happy with the information they received around the disease and its treatment. All carers also knew where to go and who to ask if there was an aspect around disease and treatment they were unsure about. All also reported a trusted relationship with at least one member of staff, which was usually their CNS and/or their consultant. This relationship was anchored in their confidence in staff's honesty, experience and knowledge. Being knowledgeable about the disease and its treatment also contributed to carers feeling they were involved in the decisions around treatment, which helped to alleviate some of the stress associated with caring for a loved one with a life threatening disease.

In relation to financial support, carers pointed to three separate strands; financial assistance and benefits advice; employment support; and parking costs. All carers were assisted in some way by a social worker, who made them aware of, and helped them complete forms for the one-off Clic Sargent grant – a non-means tested grant available to everyone with a child aged 24 and under. Social workers provided an invaluable source of support in providing benefits advice, and particularly helping carers to obtain disability living allowance. In addition, social workers were pro-active in negotiating with employers and facilitating leave and sick pay. Lastly, parents often worried about the high costs of parking on the hospital sites. In this sample, six parents were car owners, and all received in-house help with these costs whilst their child was receiving treatment.

There were two areas highlighted by parents around practical information that could be developed. The first was at the finishing treatment stage, as outlined previously. The second area, is that of educational support for carers. Given the age of this cohort, it is likely that some partners will still be in education themselves.

Physical Health

The most reported aspect of physical ill-health was, overwhelmingly, that of fatigue. Caring for a young person with cancer can be demanding, and will vary at each stage of the cancer experience, but it is especially demanding when the carer has other children at home. For five of the six parents in this study, care work was already a significant feature due to other younger children in the household. At the time of interview four parents had children aged between 12 and 14. During the period of time the young person was on the ward, carers could bring other children with them, and they would often be distracted by either the facilities on the ward, or by the youth support workers, who would involve them in activities. Some parents reported difficulties with child care, especially during hospital visits and clinic appointments.

Emotional Health

Most significant for parents and partners in this study, were the emotional dimensions of caring for a young person with cancer. For parents, in particular, the undertaking of emotional work was continuous throughout diagnosis and treatment, and could have a significant impact on mental health:

> *Doing emotion working in cancer contexts is fundamentally about managing feelings in order to sustain a sense of control over events, to stave off the nightmares of death, loss and major life change, and to promote healing (Thomas et al 2002, p538)*

One mother worked hard to manage and protect her younger children from the stark realities of the cancer ward:

> *I've had to try and bring them here but not involve them too much because this isn't normal! I don't want to have the other two kids to go through it … I think the least people that have to come and see what happens in real life the better. (Lauren, Parent)*

Lauren's extract was in contrast to William, who involved his daughter in her brother's illness from the beginning, and did not attempt to hide anything. For William and his family, this worked well, but for other siblings, being involved could create emotional distress. Kate, another parent discussed how her son, aged 17 at the time of interview, had a close relationship with his sister, and made arrangements to leave school early, in order to help care for her. Kate could see the emotional toll this was having on her son:

> *They're very, very, close and I think he could have done with tapping into that counsellor that I've got, but I don't think the option is there. (Kate, Parent)*

The TYA service does offer psychological support for siblings, however Kate was unaware of this.

Putting young people first, and hiding their own distress were also common features for carers:

> *Oh, I just keep trying. I mean if he's got such a positive attitude, why should I worry and bring him down? (Lauren, Parent)*
>
> *Even now I try my best, I try and go on as normal but it has destroyed me really.(Jennifer, Parent)*

As were resignation and fortitude:

> *Just had to get on with it, it's part of being a parent, I mean it's awful, sometimes a nightmare, but I'd rather I've been looking after him than somebody else. (Megan, Parent)*
>
> *I don't know, I just got on with it, it was just-it ended up just being part of life and I just had to get up and get on with it. (Lucy, Partner)*

These coping strategies and behaviour are in line with accepted ways of behaving around people with life threatening illnesses, or 'social feeling rules' (Duncombe & Marsden 1998). Clearly, for all carers, caring for their loved one was an unquestioned social duty. However, these 'social rules' took their toll on their emotional states in a number of ways, which included problems with sleeping, feelings of irritability, guilt, extreme sadness, deep distress, and for some parents, the stress impacted on their intimate partner and family relationships. Indeed, these emotional states resulted in at least two parents being prescribed anti-depressants by their GP, and two accessing the TYA Service psychologist, which is consistent with Grinyer's (2006) research on the emotional toll associated with caring for a TYA with cancer.

Types of Support Offered and Received

The majority of carers gained emotional support from close family members and friends, although one parent with a young family felt she had no one to confide in, or who could support her. Two parent carers specifically discussed speaking to other parents on the TYA wards, which they found helpful. In terms of direct support from the TYA service, a few carers reported that speaking to their CNS was an ongoing option, and felt this had benefited them enormously.

Another form of direct support that parents utilised was on site relaxation from the complimentary therapist. Although very few young people tended to use this service, it proved beneficial to family members and carers. The complementary therapist's role was to deliver holistic forms of therapy for young people, as well as their families and carers. This post was part-time, and funded by the Leeds Charitable Trust, which can broadly be defined as money raised for the TYA wards by families and friends. The different therapies available consisted of massage, acupuncture and reflexology. In general massage was the most popular therapy taken up by family members, and tended to be used more regularly at the older TYA unit by young people's mothers.

Notably, none of the carers interviewed reported that they had been specifically assessed for their health or psychosocial needs, although some parents would have benefitted from this. Nevertheless, all staff acknowledged that carer health was important, and although it would initially be time consuming, most believed the development of a formal assessment would be beneficial. The processes used by staff to identify carers who may be experiencing health difficulties tended to be informal and variable in manner. In the main, the majority of staff would identify carers who were thought to be struggling health-wise, through chatting with them and listening carefully. Some staff talked with carers as a matter of course, in order to identify any health difficulties, whilst others would only speak with them if they thought there may be a problem. In addition, a small number of staff utilised the TYA psychosocial MDT as a place to identify any carers who were experiencing serious health issues. Importantly, there was no consensus by staff on who should take responsibility for carer health. For example, some staff thought GP's or Oncologists should take responsibility, whilst others believed it should be a team effort, and all professional staff should be responsible for identifying physical or emotional ill-health. In practice, it tends to be an informal version of the latter strategy. What staff were all in agreement about was what they did when health needs were identified, and this was to signpost carers to other support services and GP's.

In short, the establishment of trusted clinical relationships, and the provision of medical information were very good. Financial needs were also met well. However, improvements around assessing and providing for both the physical and emotional needs of carers could be inconsistent. The value of carers' good health and how this impacts on and affects patients' experiences is significant, and early interventions with support for psychosocial needs can benefit young people in a number of ways. It can alleviate the onset of psychological distress for both carers and patients (Hodges, Humphris & Macfarlane 2005). It can contribute to more positive treatment outcomes for young people (see Groot et al, 2005). And can also contribute to positive family relations.

Recommendations

1. Health professionals to pay greater attention to the role that carer's play, and their psychosocial needs. Reassure carers that their needs are legitimate.
2. Educational support for carers.
3. Health professionals to recognise that carers tend to put the patient first, and may be reluctant to seek support for themselves.
4. Develop formal psychosocial needs assessment for carers.
5. Make carers and families aware that psychological support is available for other family members, including siblings, and for partners and close friends.
6. List of support services easily available to all staff, to help with signposting.

SERVICE COHESION AND WORKING PRACTICES

CONTEXT

There are a number of common barriers in existence that can hinder the development of an ideal model of care. These include lack of awareness of the prevalence and long term consequences of TYA cancer by politicians, policy makers, health systems, health authorities, and the public; top down approaches used by most health care systems, which do not tend to acknowledge the special needs of particular age groups; the potential lack of communication between paediatric and adult oncologists, which is necessary to manage patients effectively; lack of funding and resources; lack of patient cohort involvement; and the geographical distance to treatment (Ramphal et al 2011: 2320)

These barriers had been experienced by the TYA service either in the past, or as ongoing problems, but the service was found to have overcome, or invented innovate ways to circumvent these difficulties. This section explores how cohesion of the service is achieved from a staff perspective, through their understanding of service objectives, and how staff and systems have developed within the service to overcome the structural constraints of: service cuts, working within and across the paediatric and adult divide, managing the care and transition of young people aged 16-18, and establishing MDT team meetings.

UNDERSTANDING THE SERVICE: DESIRED OUTCOMES

Patient centred outcomes for any TYA cancer service are synonymous with those outlined in the *International Charter of Rights for Young People with Cancer*, which focus on the unique educational, social, psychological and developmental needs of teenagers and young people. All staff were asked whether they were aware of the desired outcomes of the service. Three members of the nineteen staff interviewed were able to articulate these:

> *I haven't seen any defined goals written anywhere, or anything like that, but I think that the goals are that they want to make sure young people are treated appropriately, according to their age and specific needs, and as young adults rather than being as children. And I think that they try and provide a service that is geared towards their needs, whether it's education, social… meeting their physical needs, privacy, and that sort of thing, but they do work well towards those goals, to achieve that for them. (Staff)*

The remaining participants were unsure about the service's desired outcomes:

> *What are the desired outcomes? I don't know, I don't know, maybe I just assume I know what they are.(Staff)*
>
> *Do we have some? Are they written in a policy somewhere? (Staff)*

Naming the desired outcomes proved difficult for the majority of staff interviewed. However, that is not to say that the aims of the service were not known to staff in more instinctive ways. All staff interviewed were committed to an unstated, but symbiotic medical and psychosocial philosophy of care, which was evident in responses to other questions regarding the skills required to care for young people, information sharing, MDT working, and their signposting knowledge.

Recommendations

1. Provide list of desired outcomes for the service in a variety of media and display visibly.
2. Embed goals into standard operating procedures.
3. Clearly state goals at all staff inductions.
4. Include desired outcomes in information packs given to young people and their families at the point of diagnosis.

WORKING WITHIN CONSTRUCTURAL CONSTRAINTS

The work involved in managing a TYA service is multi-faceted and can be challenging. Leaders, both clinical and non-clinical were found to be pro-active, motivated, flexible, approachable and supportive. These skills are key in any TYA service, particularly with regard to the successful cohesion and management of paediatric and adult philosophies of care, and the different working practices and systems found here. These skills become ever more pertinent when the service is split across two different sites within a city, as is the position at Leeds.

There was general recognition from all levels of staff, including senior level, that in order to operate a cohesive service a number of working practices must be promoted, and actively put into place. Throughout its development, the Leeds service has seen a number of clinical staff who have been instrumental in pushing the service forward. The following features were evident from observation as well as from staff interviews:

- Partnership working - essential at both operational and strategic levels.
- Clarification of purpose and ethos – promoting the necessity of a TYA service.
- Multi disciplinary working - working across professional boundaries – including allied health professionals in decision making and care.
- Shared Care – across sites, age groups, and philosophies of care, and at local and regional community level.
- Commitment, Motivation, Collaboration.
- Transparent and clear administrative processes.
- Sharing of good practice.

In addition, to the above features, staff need to be highly trained: having high level personal skills, the competence to work in a multidisciplinary environment, the ability to relate to young people and their significant others, and being proactive in developing the service. Ongoing training, then, is essential to ensure cohesion, knowledge and joint working.

When a service consists of a large number of components, that must be amalgamated and cohere to ensure smooth operation, there are an inevitable number of difficulties than can arise and must be overcome. These include: managing staff from different professional backgrounds; working across separate structural systems, and negotiating the paediatric/adult divide; working across separate physical spaces; ensuring trust, ownership and responsibility; and, ultimately, working within any given political and economic climate, that can affect staffing levels. The remaining sections evaluate how these difficulties were acknowledged, negotiated and often overcome.

Structural & Political Constraints - Staffing Levels

In the current political and economic climate of health reform, front-line cuts and extra work are commonplace, which can have a major impact on health care and its delivery. Half of staff interviewed voiced concerns around staff shortages on the 13-18 side of the TYA service, and believed this decreased the quality of care that young people and their significant others received:

> *Across the entire service there are a certain amount of beds, I think it's 23 but I'm not 100% on that one, and there are more bed spaces than actually beds that are staffed, if that makes sense, so I think we're a unit that can take 28 in total across all three but there are beds that are closed which means that actually there may be a suitable bed space there, but there's not enough staffing. (Staff)*
>
> *We are all extremely stretched and it's never going to get any better, because the financial situation in the NHS is such that you're never going to get any extra posts now, in fact they're going to be less and less and less and all this sort of support things, like having a clinical nurse specialist to help, having junior doctors to help, all of our nurses on the wards… all of those are getting less and less with time, and we can't delegate anything to junior doctors anymore*

> *because they all work on shifts and one week they're there and the next week they're not for the next three weeks, you know, there's no continuity. (Staff)*

Staff shortages can negatively impact on the quality of service experienced by young people. In some instances, young people have had to be admitted to the younger part of the service, and short delays in treatment can occur when there are not enough staff to cover available beds. The psychological fall-out can be wide-reaching for young people and their families, and some staff believed this was detrimental to fostering an effective environment and atmosphere:

> *It becomes a big strain on the staff on the unit, and the parents and the young people can see that on how the staff are coping. (Staff)*

Some staff also believed that when staff were seen as being under pressure, this could deter young people and their significant others from approaching them, unless they had a serious problem to discuss.

Also reported was the disjuncture between what management believed to be true, compared to the desired outcomes, and lived reality of staff and the care they were able to offer:

> *It's the quality of care that we should be delivering that is really difficult to measure, and that people don't seem to be interested in because all the audits that come through - you tick boxes that "yes you've done this bit of paper work" and "yes you've done this". But they don't-the ticking box isn't there for a new family that walks through the doors and needs just half an hour to sit and talk, or sort of listen and explain things properly, or just be there to hold somebody's hand because that's what they need. (staff)*

The establishing of relationships with young people and their families is a feature of the TYA service that sets it apart from other services. When this is perceived to be under threat, it can impact negatively on staff. The increased demands associated with staff shortages impacted on the perceived ability to deliver quality care and contributed to feelings of disempowerment, low morale, and stress for staff. And a number of staff commented on this:

> *It makes you stressed out, I think everybody on here is stressed out at the moment, but because we are a close team we all kind of carry on together, but we're just… some people are just getting to the end of their tethers. (Staff)*
>
> *We are quite stretched, and if something else needed covering, or you needed to stay a bit longer, you do! And I don't know if we'd have that kind of ethos if we didn't' all get on because we know that we just want to support each other really. (Staff)*

Limited staff means quality of care within the service can deteriorate, which often manifests in weaker communications between staff, and also between staff, and young people and their families and carers. However, as the extract above demonstrates, staff tend to mitigate this by working over and above their contracted hours, and supporting each other through this. That staff do manage to navigate their time, and juggle resources successfully, is evident from young people's reports, as well as their families and carers. Whilst many staff were unhappy with the decreased workforce and the extra work, this does not appear to reflect on the time spent with service users, as the majority of service users felt strongly about the high levels of expertise, and time spent with them, particularly in the area of information around diagnosis and treatment. To this end, although leadership was essential to establish the service and to bring all components together, it is also clear that collaborative working has developed, and now figures largely within the service.

Structural Constraints - Paediatric/Adult Divide

The difficulties in operating a 13-24 TYA service across the two separate institutional practices of paediatric and adult care can be multi-fold, with the main problems occurring for young people aged 16 and upwards. One problem is ensuring the referral of all young people aged 16 and over into the TYA service. At Leeds there are multiple points of entry for this age group: from GP's, other regional hospitals, and adult specialist sites. Staff reported that in the past, referral into the TYA service for some young people had not happened. However, staff were also in agreement that referrals had improved tremendously, and that the introduction of an MDT administrator had contributed significantly to this situation. In addition, the current trend in the separation of adult and children's hospitals has highlighted a general problem for young people transitioning from paediatric to adult care. This separation not only highlights pre-existing transition issues, but can also compound them, especially in terms of cohesion and smooth communication between paediatric and adult services. Nevertheless, this transition problem occurs at national level, affecting most specialisms. Having separate physical spaces for paediatric and adult care can also add to an existing problem for young people aged 16-18, who are in the so called 'grey zone', and this is looked at next.

Structural Constraints - 16 to 18 'Grey Zone'

The 16-18 'grey zone' refers to the traditional working and cultural practices found in the different philosophies of care that paediatric and adult care is based on. A number of problems for young people aged 16-18 can ensue from this, which can, in turn, decrease the quality of service they receive, Ensuring best quality care for young people aged 16-18 can be a complex process, with the main problems due to the paediatric/adult division of care, differences in culture and working practices, and responsibility issues. At Leeds, paediatric oncology cater for young people up to their 19th birthday, and have full administrative and medical access to many children's services. However, some children's services stop at age 16, and responsibility is passed to adult services:

> *We have patients on our ward who need surgical input and the paediatric surgeons say 'too old' and the adult surgeons are based in the other hospital and they say 'too busy' you know, they [16-18's] don't have anywhere near as good a service as a child does. (Staff)*

This mismatch of the age at which care changes is one reason for the problems encountered, particularly around who takes responsibility for the young person. This is compounded by some specialisms, who do not perceive TYA's as a distinctive cohort for health care. However, it is important to point out that, in general, it was the *differences* between and across paediatric and adult working practices that obscured responsibility for young people aged 16-18, and presented problems. The same differences in working practices could also cause difficulties in shared community care, and transition to adult services. This ongoing complication was frustrating to the majority of staff interviewed, and overcoming these obstacles frequently amounted to labour intensive communications with other specialist departments:

> *If nobody talks to me I'll just talk to them until they have to talk to me! But it depends on how much time you've got. (Staff)*
>
> *So, the strategy is to spend a lot of time ringing around, finding somebody, persuading people, escalating it to the consultants, we escalate it to the consultants at surgeon level, surgeons at the Bexley, and then eventually it will get sorted out, but it usually takes a whole day of argy-bargee really before it's sorted. (Staff)*

Nevertheless, leadership roles taken on by individuals have ensured that collaborative relationships continued to be developed, and staff reported that difficulties were decreasing.

Within the Leeds service, space and capacity is also problematic. The specialist paediatric building is only physically able to hold patient numbers up to the age of 16, and this is a contributing factor to the problems of cohesive care for 16-18 year olds. Other differences in working practices include increased numbers of patients carried by adult consultants, different training systems, and differences in day to day clinical responsibilities. Staff also mentioned problems with the frequent rotation and shifts of junior physicians, different chemotherapy regimens, and different pharmacological requirements.

The problems associated with young people aged 16-18 are largely overcome by a dedicated CNS who works with this age group. The CNS acts as the main point of contact and mediates around their clinical and psychosocial care. It is imperative that the CNS adopts a leadership position, and liaises with appropriate individuals, so as to ensure best quality care is always given. Importantly, the CNS sits in the middle of, and thus acts as a link between the 13-16 and 18-25 age groups, and needs to be proactive in ensuring the sharing of information between different TYA sites and specialisms. This includes attending medical and psychosocial MDT meetings and reporting to all appropriate staff on decisions around diagnosis, treatment, and psychosocial needs. In this way, any feelings of insecurity, low morale and feeling 'out of the loop' by staff, in relation to care for 16-18 year olds, can be alleviated.

Structural Constraints - Transition

Transition from paediatric to adult care is a complex process on its own, in particular, the transition from family oriented to individual care. However, it is compounded by the structural systems found in each specialism. In general, paediatric care provides for up to ages 16, whilst adult care begins at 16. As the TYA service at Leeds encompasses the age range 13-19, this can lead to significant problems. Another structural difficulty centres around paediatric oncology covering all childhood solid tumours, but in adult care, disease becomes site specialised. Therefore, for young people and staff, it is not just transferring to a similar adult disease specialist, but rather many different specialists. In addition, transition is dependent on other contingencies, such as age at diagnosis, type of disease, length of treatment, and whether the young person is on a clinical trial, and where this trial is located. These complexities are reflected in the following:

> *It's really difficult because … say they're diagnosed at 17 with an osteosarcoma onto [ward] and they spend a good twelve months with them and that's where their care team are, I think it's quite difficult for them to have any kind of transition when they're quite comfortable with the care they're getting. I think it's so difficult, it depends again down to that individual. Sometimes doctors aren't happy to relinquish people either - to allow them to go over to adults, but again it's a choice (Staff)*

This extract outlines how physicians may be distrustful of the transition process, and/or handing over patients to the responsibility of others. This is understandable, given the relationships that have been established with the young person over time, and the desire to protect and ensure continuity of care.

The paediatric/adult divide was recognised by most staff, compelling them to hold an understanding of, and work within, conflicting structural systems when they spoke about transition and the ages young people should remain on the younger ward. Indeed, judging when young people might transition could begin at diagnosis:

> *Well it's looking at each individual. If you have an 18 year old who has just been diagnosed and is going to have four years of treatment, it would make sense for them to be over there on the St James's site … The problems come with the 16, 17 year olds who sort of float along in the middle because of the way that adult services are set up. In the majority of specialties, you move into adult services at age 16. I don't think that [ward] should stop at age 16, personally I think that 18 is right for that, but the problems come when all the other specialities for adults are at the St James's site. (Staff)*

Being diagnosed with cancer at age 16 or 17, then, could cause dilemmas regarding where the young person would be best placed for treatment, taking into account their length of treatment, their ages at the start and end of treatment, and an appropriate age for transitioning to the young adult ward.

Other factors identified by staff that influenced decisions around when young people should begin transition, included individual levels of maturity, child protection issues, and clinical trials. For a young person to complete their trial it is necessary to continue treatment and follow-up care at the trial location. This inevitably leads to some TYA's remaining within the 13-18 TYA service, well past their 18th birthday.

It is not unusual, for young people themselves to delay transition. The patient choice ethos that underpins the service, strives to create empowerment for young people, and there is a tendency to exercise this choice by remaining in familiar surroundings. This was often supported by staff who thought retaining continuity of care was important for young people. Indeed, young people's familiarity with staff, and the relationships that had been established, sometimes over a number of years, created emotional dilemmas for staff. So much so, that some staff were reluctant to consider intermediate transitions to the young adult cancer ward. Nevertheless, some staff did agree that transition processes for young people need to be developed:

> *I think, we need to start looking at transition to the adult ward and we should be looking at 18, 19 year olds, not 16 and 17 year olds first. So that's an ongoing discussion with colleagues … I think there are some around that we possibly haven't even asked the question. (Staff)*

What this extract also shows, is that there is still some confusion around conventional transition ages. This member of staff is drawing on the normative age of transitioning i.e. 16 or 17, and dismissing this as too young. This is likely down to staff having to engage with, and think within, two competing ideologies. However, the service clearly caters for ages 13-18, and there is no question of transitioning before then. Nonetheless, young people, at around age 18, do need to be encouraged to transition to the older TYA service, who are fully equipped to deal with their medical and psychosocial needs.

Clearly, the TYA service at Leeds must work within existing and conflicting structural systems, and negotiate a highly complex network of processes, in order to provide specialist care for TYA's. One of the most demanding obstacles is creating a feasible space from which to provide care for young people aged 16-18. There is a need to develop transition for young people on the 13-18 TYA site, which ideally should begin to be introduced at around ages 17-18. For most young people, and in order to affect a smoother, and less abrupt cultural change, it would be appropriate to transition first to the 18-25 TYA service, with a dedicated lead for organising and mediating with appropriate personnel in adult specialisms.

Recommendations

1. Systematic process required to maintain connections, and ensure cohesion between the 13-16, 16-18 and 18-25 TYA aspects of the service.
2. Dedicated lead to organise and mediate transition. For most young people, dependent on their individual circumstances, it would be appropriate to transition from the 13-16 TYA unit to the 18-25 TYA unit first:

    - Dedicated worker to be funded or identified to introduce and manage transition
    - Ideal age for transition to be agreed upon and introduced
    - Preparation times before transition occurs
    - What will be included in transition – pre-transfer visit, information etc.
    - Administrative procedures for transfer, i.e., referral letter etc.
    - Guidelines to also account for and encompass individual circumstances

MULTIDISCIPLINARY CLINICAL AND PSYCHOSOCIAL MEETINGS

MDT meetings in the TYA service refers to a wide range of professionals from different backgrounds. Their aim is to "bring together staff with the necessary knowledge, skills and experience to ensure high quality diagnosis, treatment and care" (NCAT 2010 p5), within both a clinical *and* psychosocial context. Dependent on the age of the young person, their diagnosis and treatment will be discussed at either a paediatric or adult site specific MDT meeting, as well as at a separate TYA MDT meeting. For some services the TYA

MDT meeting includes both the clinical aspect, i.e., diagnosis, staging and treatment plans, as well as the psychosocial needs of TYA's. Where possible, however, it can be useful to hold separate TYA psychosocial MDT meetings to discuss young people's psychological and social needs, as well as their family and carer needs. MDT meetings, then, should be attended by all those who will be involved in the care of a young person. The following professionals can be required for one TYA patient at different points during their cancer:

- Treating Oncologist
- Pathologist/Cytogeneticist
- Radiologist
- Surgeon
- Neurosurgeon
- Clinical Oncologist
- Paediatric haematologist
- Key-worker
- Specialist nurses
- Nurses – inpatient / outpatient care
- Specialist pharmacist
- Palliative care specialists
- Activities/youth support co-ordinators
- Psychological services
- Appropriate allied health professionals: specialist outreach nurse, social workers, teachers, physiotherapists, dieticians, and so on. (Pearce 2009: 151)

Despite its length, this list is not exhaustive, as the needs of TYA's will vary at various points in their disease, and other areas of expertise may also be required.

There are a number of obstacles and barriers that can hinder the establishment of collaborative and cohesive MDT meetings. These include: time and resources, many clinicians simply do not have the time to attend extra MDT's, and may view a separate MDT as duplication; working practices will most likely be different, with different structures and systems; TYA care is not yet recognised as a specialism, and must straddle and work within both paediatric and adult philosophies of care; ownership of patients can become fragmented, and may create negativity and insecurity; TYA care is in its early stages, and the body of research, including longitudinal research, that is necessary to convince of its specialism and improved outcomes is still in its formative period (Kelly & Gibson 2008; Morgan 2005)

The Leeds Service has developed considerably (see Morgan 2005), and currently holds a number of weekly MDT meetings, these include a paediatric clinical MDT; adult site specific clinical MDT's, where young people are discussed and also referred into the TYA service; a TYA clinical MDT, to which both paediatric and adult site specific consultant oncologists are invited; a radiotherapy TYA MDT; a paediatric psychosocial MDT, where young people up to the age of 18 are discussed; and a dedicated TYA psychosocial MDT, that discusses TYA's from age 13-25.

TYA Clinical Multidisciplinary Team Meetings

Overall, the TYA clinical meetings worked well, but its development has been subject to many of the barriers outlined above, which the team have overcome exceptionally well. Working across different philosophies of care, however, can also create problems, and, in reality, a TYA philosophy of care has also been developed at Leeds, which, if it is to work seamlessly and cohesively must develop and fit within existing adult models. It is this particular situation that appears to cause the main problems, in particular around referral systems. For some staff there was a worry that delays into the TYA system had occurred for some young people in the past. These delays mainly stem from administrative procedures, as well as time constraints from the various professionals that need to be involved in the care of a young person. The consequences of these type of delays, however, can be far-reaching, especially in treatment management. In terms of administrative procedures, some staff were unsure of the exact procedures around referral.

> *I think probably feeding into that, and this is probably my fault, I don't quite understand the process of them being referred in and I don't know whether there's one person that's a gatekeeper or whether there's two or three or what happens with that, and what the process is. (Staff)*

Although standard operating procedures for referral to MDT's do exist, referrals are often made from multiple sites. Notwithstanding this, staff have observed an increase in referrals due to the concerted efforts of TYA staff in reassuring and educating the vast number of site specific departments:

> *There's probably fewer patients being missed and I think that's a real testament to the workers, the kind of lead group (Staff)*

A number of staff, when asked what they would change about the service, however, did express concern on how MDT meetings could be better organised. In the main, this was down to time constraints on staff, which meant they could not always attend. This could sometimes lead to tension, uncertainty, and a perceived sense of fragmentation.

The most common barriers for optimum MDT meeting collaboration, was the fact that the service is split over two sites. Gathering busy people together across two sites has proved highly complex for the TYA clinical MDT. Nevertheless, the advent of technology means video links have now been utilised to overcome geographical difficulties. Video link is viewed, by most, as the next best thing to assembling the relevant multidisciplinary staff together. However, problems still arise here. Technology can occasionally fail, which is frustrating for all concerned. More problematic was the lack of face to face contact:

> *It is certainly better than not meeting at all, it's not as good as meeting in person but it's the only way forward I think. (Staff)*
>
> *Being in two places is not the same as being in the same room as somebody, and you can't see people's facial expressions and you can't figure out what they're thinking just by looking at them and have a proper discussion. (Staff)*

The split site situation does cause issues, however, improving the teething problems associated with the video technology will help. In terms of face to face contact, staff appear to be adapting to this. In time, becoming more familiar with working in this new way, will ensure the TYA Clinical MDT is more satisfying, and works well for all concerned.

TYA Psychosocial Multidisciplinary Team Meetings

On the whole the psychosocial meetings worked well, and also functioned as a space for peer/staff support. The difficulties that could be encountered tended to be related to working practices, job roles, set patterns and responsibilities, and the development of the TYA psychosocial meeting itself. The following extract raised all these factors:

> *We can be seen to be doing something a bit maverick, sometimes, without a great deal of consultation sometimes-an example would be the establishment of the TYA psychosocial meeting, when that first started happening, who was in consultation that that was going to happen? And that it was 13 upwards, and that caused a lot of friction! It's trying to please everybody and you just can't do it and I think it gives rise to a lot of frustrations, people have got established job plans, working patterns and trying to pull all that together is very hard and very difficult and it leads to tension and nobody likes to be told what to do, and if it comes across as that, it creates tension: "Why can't they fit in with us? And vice versa". Lots of big egos particularly in the medical too; both the paediatric teams and the adult teams. (Staff)*

At Leeds there are two separate psychosocial meetings held at the two sites: the 13-18 TYA meeting is included in the paediatric psychosocial meeting at the LGI, but there is also a TYA psychosocial meeting held at St James' that includes all TYA's aged 13-25. Some staff mentioned that medical staff did not always attend these meetings.

Staff in the younger part of the service felt there was a lack of representation from TYA staff at the paediatric meeting. In addition, the same staff felt there was a lack of representation from the younger part of the service at the general TYA psychosocial meeting. Again, this is an area where the split site set-up compounded difficulties. Ward staff were often too busy or, indeed, too short-staffed to attend, and felt that meeting discussions and decisions were not always fed back for young people who were also patients at the LGI. Communication is paramount, and if medical staff cannot find the time to attend the TYA psychosocial meeting, then regular feed-back from a dedicated member of staff is vital.

There was a feeling that ward staff should be attending the meetings, but that staff cuts meant that the possibility of this had decreased drastically. The result of this is that ward nurses were at risk of not receiving the support from psychosocial meetings that would benefit them. Information and feed-back is best done through personal discussion, and a dedicated or lead worker who could attend all MDT meetings and feed-back to all relevant staff would be advantageous.

Recommendations

1. Referral systems to be made more transparent.
2. Systematic process required for regular feed-back/update of clinical and psychosocial meetings to 13-18 and 18-25 TYA ward staff, as well as others involved in the care of the young person. This will help to combat staff fragmentation, and alleviate staff anxiety and uncertainty.

CONCLUSIONS AND FURTHER RESEARCH

The findings from this study clearly demonstrate how important specialist care is for young people diagnosed with cancer. The model of collaborative and multidisciplinary care that has evolved at Leeds has developed within a framework that views patients and their needs as central, and is thus able to effectively tailor support at an individual level. The core aspects that have developed also synchronise with research and policy that has already occurred, as well as research that is still in development (see BRIGHTLIGHT study). In addition, the service is in line with international thinking, and corresponds closely with the *International Charter of Rights for Young People with Cancer*.

The Leeds model of care has been forged amidst two existing, but very different ideological ways of working. Namely, paediatric health and adult health care. In order to function smoothly, the staff that provide this care must, engage with, and incorporate the cultures and working practices of both ideological institutions. This type of care, in effect, reshapes how general paediatric services care for teenagers aged 13-15 in the area of oncology, and also how specialist adult oncology departments care for young people aged 16-24. Together, this fundamentally reshapes the experiences of young people and their families and carers.

MEETING PATIENT EXPECTATIONS, AND INFORMATION SHARING

The expertise and dedication of staff were recognised by service users as an outstanding feature of the service. Trusted clinical relationships were almost always established and contributed significantly to young people and carers' confidence in the care they received. The majority of information shared with young people and carers was of a high standard; was highly valued; and met patient expectations well. Young people were involved in a number of ways in decisions about their treatment, and the numbers involved in clinical trials were well above national averages.

There were a number of key areas where information provision could be improved. A general information pack given out at the beginning of the cancer journey, would mean all support services are listed and can be referred to at later dates, or when needed. Fertility information could be improved to ensure that all young people are given information about their fertility, whether there is a risk or not. Fertility guidelines may also be helpful to professionals when making decisions about sharing sensitive information with younger teenagers, and judging when, to whom, and/or which members of TYA's families should be involved when sharing this information. Lastly, the finishing treatment stage could be difficult for many young people and their carers. Although participants reported that CNS's were always available to allay fears and provide advice, an information pack summarising diagnosis and treatment, and outlining what to expect after treatment finishes would also be useful.

Recommendations are as follows:

- Information pack to be given out at diagnosis, outlining what the service provides: named consultant, named key-worker, learning mentor, social worker, youth co-ordinator, psychologist, as well as a summary of roles, and how they can assist young people, and their families and carers.
- Uniform guidelines to be developed around providing fertility information to young people.
- Finishing treatment information packs to be given to all young people. To include diagnosis and treatment summaries, follow up periods, symptom checks, late effects, prevention and dietary advice, sexual relations advice, drugs and alcohol advice, support groups, and legal rights around employment and insurance etc.

MULTIDISCIPLINARY AND PSYCHOSOCIAL SUPPORT

On the whole, the multidisciplinary team worked collectively and very well together. Participants were highly appreciative of the clinical nurse specialists and the youth support co-ordinators who, together, provided a much needed sense of normality for young people. They also provided emotional support during young people's treatments, which was highly valued, as well as organising social outings, get-togethers, and support groups after treatment had finished.

Other areas of support that participants reported as beneficial were social worker and educational support. Social workers were invaluable for financial advice around welfare benefits, employment and obtaining various grants, but their professional skills could be utilised more widely. Educational support was provided as standard for young people in compulsory education, as well as a learning mentor. The learning mentor was particularly useful for young people who were in further or higher education, but could improve by tightening up their communication systems.

Psychological support was available to young people and their families from various sources, and at various levels. In particular, and along with other clinical and ward staff, clinical nurse specialists were the main providers of ongoing emotional and psychological support to young people, and their family and carers. Very few young people actually accessed support from trained psychologists. Indeed, some young people reported a reluctance to discuss emotional and personal issues in general, but far more expressed their unwillingness to speak with professional psychologists directly. In view of the psychological and emotional problems around bereavement, fertility, social relationships and isolation on finishing treatment, the stigma attached to psychological support along with young people's reluctance to access it, meant that some emotional problems remained unidentified.

One area that could be improved was around carer health. For carers, assessment of their physical and emotional needs tended to be carried out informally, and could be inconsistent. A formal assessment tool for carer health would benefit not only the carers themselves, but also young people and the service as a whole.

Recommendations are as follows:

- To explore psychological support and how young people engage with it. The development of a psychosocial screening tool should also be considered.
- Develop formal assessment tool for carers' psychosocial and physical health needs.

SERVICE COHESION, WORKING PRACTICES & DESIRED OUTCOMES

All staff were committed to an ethos that medical and psychosocial care are symbiotic, and were central to best practice for teenage and young adult care. Articulating the desired outcomes of the service, however, was difficult for most of the staff interviewed. Instead, service aims were understood in an intrinsic manner, that was demonstrated through the unique philosophy of care that had developed over a number of years. Staff understood the skills required to care for this age cohort, and this could be seen in practice through information sharing, multidisciplinary team working and signposting knowledge and, perhaps most importantly, through the responses from participants, who directed high praise at both the service and staff.

The multidisciplinary clinical and psychosocial team meetings were a key feature of the service, and had developed to a good standard. However, a number of obstacles associated with the current climate of resource cuts and shortages, as well as issues related to working across a split site have had to be overcome. Gathering all relevant staff together for the meetings was particularly difficult. Nevertheless, dedicated staff, good leadership, collaborative and collective working, as well as video technology, had alleviated this to a large extent. That some key members of staff were unable to attend meetings could feed into a tendency to view different age groups within the service as separate entities, and this was one area that could be strengthened and reinforced to encourage unity.

Having to work across the different working practices contained within adult and paediatric cultures was a major barrier faced by the Leeds team, which impacted directly on the management and care of 16-18 year olds. This could be frustrating for staff, but their labour intensive communications with other specialist departments, and leadership by individuals ensured cooperative relationships were developed on an ongoing basis. There is still a way to go before the whole hospital becomes wedded to this unique form of care, but difficulties had been significantly reduced.

Finally, transition for young adults was highly complex, with age at diagnosis, length of treatment, type of disease, whether the young person was involved in a clinical trial, and the problems associated with the paediatric/adult divide all having a bearing on when transition occurred. This could delay the transition process. For most young people, and in order to affect a smoother, and less abrupt cultural change, it would be appropriate to transition to the 18-25 TYA service as an interim before transferring to general adult services.

Recommendations are as follows:

- Provide list of desired outcomes, print in a variety of mediums, and visibly display.
- Systematic process required for regular feed-back of clinical and psychosocial meetings to all 13-18 and 18-25 TYA staff involved in the care of the young person.
- Systematic process required to maintain connections, and ensure cohesion between the 13-16, 16-18 and 18-25 aspects of the service.
- Dedicated lead to organise and mediate transition.

FURTHER RESEARCH

Many aspects of the service were evaluated and, therefore, restrictions have been necessary regarding the level of detail that can be reported on. Nevertheless, aspects of the service have been highlighted that would benefit from more in-depth exploration. These areas include psychological support and the complex needs of TYA's; how fertility issues are dealt with, and young people's experiences of this; and also the development of psychosocial health needs assessments for carers.

Time and resources did not extend to evaluating the follow-up service for young people that is provided at Leeds, or the late-effects clinics, nor any transition to adult services that young people may have experienced, and these are also clear areas that are in need of further research.

The results of this regional study also highlights the need for a national evaluation of the benefits of specialist cancer services for TYA's. The BRIGHTLIGHT study, which has recently begun, has a wider remit and aims to Identify the core parts of specialist services, as well as the outcomes for young people and their association with specialist care, and the costs to both young people and the health service (www.thebrightlightstudy.co.uk).

REFERENCES

Anderson, B. (2002) ‘Biobehavioural Outcomes Following Psychological Interventions for Cancer Patients.’ *Journal of Consultant Clinical Psychology* 70(3): 590-610.

Boudioni, M., Mossman, J., Boulton, M., Ramirez, A., Moynihan, C. & Leydon, G. (2000). ‘An evaluation of a cancer counselling service.’ *European Journal of Cancer Care*, 9, 212-220.

Bleyer A., Budd T., Montello M. (2006) ‘Adolescents and Young Adults with Cancer: The Scope of the Problem and Criticality of Clinical Trials.’ *Cancer* Supplement, Volume 107, No. 7, 1645-1655.

Burke ME, Albritton K, Marina N. Challenges in the recruitment of adolescents and young adults to cancer clinical trials. Cancer. 2007;110:2385–2393.

Crawshaw, M. & Sloper P (2006) *A Qualitative Study of the Experiences of Teenagers and Young Adults when Faced with Possible or Actual Fertility Impairment Following Cancer Treatment*. http://php.york.ac.uk/inst/spru/pubs/183

Accessed 22-10.2012.

Department of Health (1995) *A Policy Framework for Commissioning Cancer Services (Calman-Hine Report).* London: The Stationery Office.

Department of Health (2000) *The NHS Cancer Plan: A Plan for Investment. A Plan for Reform.* London: HMSO.

Department of Health (2007) *The Cancer Reform Strategy*. London: DOH.

Duncombe, J., & Marsden, D. (1998) ‘Stepford Wives and Hollow Men? Doing Emotion Work, Doing Gender and authenticity in Intimate Heterosexual Relationships.’ In G. Bendelow, & S.J. Williams (Eds) *Emotions in Social Life: Critical Themes and Contemporary Issues*. London: Routledge.

Grinyer A. (2006) ‘Caring for a Young Adult with Cancer: The Impact on Mothers’ Health.’ *Health and Social Care in the Community* 14(4), 311-318.

Groot, J., Mah, K., Fyles, A., Winton, S., Greenwood, S., Depetrillo, A. & Devins, G. (2005). ‘The psychosocial impact of cervical cancer among affected women and their partners.’ *International Journal of Gynaecological Cancer*, 15, 918-925.

Hancock, K., Clayton, J.M., Parker, S.M., Walder, S., Butow, P.N., Carrick, S., (2007) ‘Discrepant Perceptions About End-of-Life Communication: A Systematic Review.’ *Journal of Pain and Symptom Management*, Vol. 34, No. 2.

Harvey, Peter (2004) Extended and Updated version of ‘After the Treatment Finishes. *Cancer Counselling Trust*. Accessed 03.09.2012.

http://www.cancercounselling.org.uk/northsouth/extra4.nsf/WebResHarvey?OpenView&ExpandAll&Count=500

Hodges, L.J., Humphris, G.M., Macfarlane, G. (2005) ‘A Meta-Analytic Investigation of the Relationship Between the Psychological Distress of Cancer Patients and their Carers.’ *Social Science and Medicine*, 60, 1-12

Kelly, D., Gibson, F. (2008) ‘Developing an Integrated Approach to the Care of Adolescents and Young Adults with Cancer.’ In D. Kelly & F. Gibson (Eds) *Cancer Care for Adolescents and Young* Adults. London: Blackwell Publishing.

Koch S.V., (2004) ‘Educational Attainment Among Survivors of Childhood Cancer: A Population-based Cohort Study in Denmark.’ *British Journal of Cancer,* 91(5) 923-928.

Kristal A.R., Shattuck A.L., Bowen D.J., Sponzo R.W., Nixon D.W. (1997) ‘Feasibility of Using Volunteer Research Staff to Deliver and Evaluate a Low-Fat Dietary Intervention.’ *The American Cancer Society Breast Cancer Dietary Intervention Project. Cancer Epidemiology, Biomarkers and Prevention*. 1997; 6:459-467.

Kyngäs H., Mikkonen R., Nousiainen E.M. (2001) ‘Coping with the onset of cancer: Coping strategies and resources of young people with cancer.' *European Journal of Cancer Care*, 2001;10:6–11.

Lewis, I., Morgan, S. (2007) 'Models of Care and Specialized Units.' In W.A Bleyer & R.D. Barr (Eds) *Cancer in Adolescents and Young Adults*. New York: Springer.

Maunsell, E., Brisson, J., Deschenes L. (1992) 'Psychological Distress After Initial Treatment of Breast Cancer. *Cancer* 1992; 70:120-125.

Mason, J. (2002) (2nd Ed) *Qualitative Researching.* London: Sage.

McBrideJ.S., Musselman D.L., Porter M.R., Reed D.A., Nemeroff C.B. (2000) 'Depression in Patients with Cancer: Diagnosis, Biology, and Treatment.' *Archives of General Psychiatry* 1995: 52: 89-99.

Miles, M. & Huberman, A. (1994) (2nd Ed.) *Qualitative Data Analysis*. Thousand Oaks: Sage.

Mitchell, T. (2007). 'The social and emotional toll of chemotherapy patient's perspectives.' *European Journal of Cancer Care*, 9, 39-47.

Morgan, S. (2005) 'Managing Professional Relationships across the services.' In T.O.B. Eden, R.D. Barr, A. Bleyer, M. Whiteson (Eds) (2nd Ed) *Cancer and the Adolescent*. Oxford: Blackwell.

National Cancer Action Team (2010) *Characteristics of an Effective Multidisciplinary Team*. Accessed September 2012.

http://ncat.nhs.uk/sites/default/files/NCATMDTCharacteristics.pdf

National Cancer Survivorship Initiative (2012) *Speaking a Different Language: Does the Terminology Used in Cancer Services Cause Confusion for Bothe Patients and Health Professionals*? Accessed July 2012.

http://www.ncsi.org.uk/wp-content/uploads/Speaking-a-different-language.pdf

National Institute for Health and Clinical Excellence (2005) *Improving Outcomes with Children and Young People with Cancer: The Evidence Review*. London: NICE

National Institute for Health and Clinical Excellence (2005) *Improving Outcomes with Children and Young People with Cancer: The Manual*. London: NICE

National Institute for Health and Clinical Excellence (2012) *Fertility: Assessment and Treatment for People with Fertility Problems (Update)*. Draft for Consultation, May 2012.

O'Hara, C., Moran, A. (2012) *Survival in Teenagers and Young Adults with Cancer in the UK*. National Cancer Intelligence Network.

Olsen, P.R., Harder, I. (2009) 'Keeping Their World Together – Meanings and Actions Created Through Network-Focused Nursing in Teenager and Young Adult Cancer Care.' *Cancer Nursing*, Vol. 32, No. 6, 493-502

Nichols, M.L. (1995) 'Social Support and Coping in Young Adolescents with Cancer.' *Pediatric Nursing*, 21, 235-240

Palmer, S., Mitchell, A., Thompson, K. Sexton, M. (2007) 'Unmet Needs Among Adolescent Cancer Patients: A Pilot Study.' *Palliative Support Care*, 5, 127-134.

Payne D., Kennedy A., Kretzer V., Turner E., Shannon P., Viner R. (2011) 'Developing and Running an Adolescent Inpatient Ward.' *Archives of disease in childhood - Education & Practice Edition*, September 2011.

Pearce, S. (2009) 'Policy and Practice in Teenage and Young Adult Cancer Care in England: Looking to the future.' *European Journal of Oncology Nursing*, 13 pp149-153.

Pearce, S., Gibson, F., Fern, L.(2010) *The 'Essence of Care' for Teenagers and Young Adults with Cancer: A National Longitudinal Study to Assess the Benefits of Specialist Care.* London: University College L

Pini, S. (2009) 'Education Mentoring for Teenagers and Young Adults with Cancer.' *British Journal of Nursing*, 18(11) 1316-1319.

Ramphal R., Meyer R., Schacter B., Rogers P., Pinkerton R. (2011) 'Active Therapy and Models of Care for Adolescents and Young Adults with Cancer.' *Cancer*, 2011; 117 (10 Supplement): 2316-22.

Ritchie M. A. (2001) ‘Sources of Emotional Support for Adolescents With Cancer.’ *Journal of Pediatric Oncology Nursing* 2001 18: 105-110.

Shnorhavorian, M., Johnson, R., Shear, S.B., Wilfond, B.S. (2011) ‘Responding to Adolescents with Cancer Who Refuse Sperm Banking: When “No” Should Not be the Last Word.’ *Journal of Adolescent and Young Adult Oncology*, Volume 1, Number 3, 114-117.

Smith S. (2004) ‘Adolescent Units - An Evidence-Based Approach to Quality Nursing in Adolescent Care.’ *European Journal of Oncology Nursing*, **8**, 20-29.

Smith, S., Case, L. (2012) *A Blueprint of Care for Teenagers and Young Adults with Cancer*. London: Teenage Cancer Trust.

Soothill, K., Morris S.M., Thomas, C., Harman J.C., Francis, B., McIllmurray, M.B. (2003) ‘The Universal, Situational, and Personal Needs of Cancer Patients and their Main Carers.’ *European Journal of Oncology Nursing* 7(1), 5-13

Steptoe, A., Sutcliffe, I., Allen, B., Coombes, C. (1991) Satisfaction With Communication, Medical Knowledge, And Coping Style In Patients With Metastatic Cancer. *Social Science & Medicine* 32(6): 627-632.

Stavri, P.Z. (2001) Personal Health Information-Seeking: A Qualitative Review Of The Literature. *MEDINFO*. 10:1484-8.

Taylor, R.M., Fern, L., Whelan, J., Pearce, S. Grew, T., Millington, H., Ashton, J., Brooman, K., Starkey, C., Gibson, F. (2011) ‘Your Place or Mine? Priorities for a Specialist Teenage and Young Adult Cancer Unit: Disparity Between TYA and Professional Perceptions. *Journal of Adolescent and Young Adult Oncology* Vol. 1, No 3, 145-150.

Thomas, C., Morris, S.M., Soothill, K., McIllmurray, M., Francis, B., Harman, J. (2001) *What are the Psychosocial Needs of Cancer Patients and Their Main Carers? A Study of User Experience of Cancer Services with particular reference to Psychosocial Need*. The Institute for Health Research, Lancaster University.

Thomas, C., Morris, S.M., Carman, J.C. (2002) ‘Companions Through Cancer: The Care Given by Informal Carers in Cancer Contexts.’ *Social Science & Medicine*, 54, 529-544.

Weber, R.P. (1990) (2nd Ed.) *Basic Content Analysis*. Newbury Park: Sage.

Whelan J. (2003) ‘Where Should Teenagers with Cancer be Treated?’ *European Journal of Cancer*, 39, 2573-2578.

Whelan J. S., Fern L. A. (2008) ‘Poor Accrual of Teenagers and Young Adults into Clinical Trials in the UK.’ *The Lancet* Vol 9, 306-307. Accessed 25.08.2011.

http://download.thelancet.com/pdfs/journals/lanonc/PIIS1470204508700809.pdf?id=e16241398b8eb460:67ac7f42:132019e35c1:-129b1314289002022

Wilkinson J. (2003) ‘Young People with Cancer - How Should Their Care be Organised?’ *European Journal of Cancer Care*, 12, 65–70.

Whiteson M. (2003) ‘The Teenage Cancer Trust – Advocating a Model for Teenage Cancer Services.’ *European Journal of Cancer*, 39, 2688-2693

Whiteson, M. (2005) ‘A right not a privilege!’ in T. O. B. Eden, R. D. Barr, A. Bleyer & M. Whiteson (Eds) (2nd Ed) *Cancer and the adolescent,* pp 1 – 10, Oxford: Blackwell Publishing.

Zebrack, B.J., Casillas, J., Nohr, L., Adams, H., Zelter, L.K. (2005) ‘Fertility Isues for Young Adults Survivors of Childhood Cancer.’ *Psycho-Oncology* **13**: 689-699.

APPENDIX I PARTICIPANT DOCUMENTATION

PARTICIPANT INFORMATION SHEET **September 2011**

Project Title: Project title: Evaluation of the Teenage and Young Adult Cancer Service, Leeds.

Why are we evaluating the teenage and young adult cancer service?

We want to make sure that we are providing the best possible care for young people with cancer. With this in mind we also want to identify any gaps in the service - by this we mean something that you might need, but that we don't provide, as well as identifying any areas that might need improving. Lastly, we want to understand exactly what we do that is positive and beneficial to you. In this way, we can compare our service at Leeds with other services, and other services can see what we do.

Why have I been approached?

To enable us to evaluate the service we need to gather the views and experiences from young people who have used the service. To paint an even wider picture we also want to talk to family members, friends and partners, as well as to staff who work within the service.

Do I have to take part?

No. Participation is voluntary. If you change your mind about taking part in this evaluation you can withdraw at any point during the interview, and at any time in the two weeks following the interview. You can withdraw by contacting me on email Carole.Wright@leedsth.nhs.uk. If you decide to withdraw, all your data will be destroyed and will not be used in this evaluation. There are no consequences to deciding that you no longer wish to participate in the evaluation.

What will happen if I take part?

We will arrange a convenient time to carry out an interview. The interview will be audio recorded, and will take place within either of the Leeds hospitals, or at another more convenient location. The interview will last for approximately half to one hour, and you may take a break at any time. During the interviews you will be asked questions about your experiences of being treated at Leeds and using the service.

What are the possible benefits of taking part?

There will be no direct rewards for taking part, however, your views and experiences will help us to make decisions about how effective the service is, and will help to inform any changes that might need to be made. This also means that any young people who are diagnosed with cancer in the future will experience a service that you have helped to improve.

What will happen to the results of the evaluation?

The results will be written up for publication on the Teenage Cancer Trust website, and in peer reviewed academic and medical journals. The results will also be shared and presented at a number of conferences and workshops that focus on teenagers and young adults with cancer.

Who is funding the research?

This evaluation project is funded for two years by the Knowledge Transfer Partnership Programme, in partnership with the Teenage Cancer Trust, Coventry University and the NHS.

Who has approved this evaluation?

Leeds Teaching Hospital, Trust Directorates; Coventry University.

Contact for further information

Sue Morgan, Lead Nurse Consultant, Teenage Cancer Trust: Sue.Morgan@leedsth.nhs.uk
Dr Carole Wright: Carole.Wright@leedsth.nhs.uk

INFORMED CONSENT

Project title: Evaluation of the Teenage and Young Adult Cancer Service, Leeds.

We are carrying out an evaluation on the Teenage and Young Adult Cancer Service at St James' Hospital, Leeds, and Leeds General Infirmary. The Purpose of this evaluation is three-fold: it aims to define the model currently in use; to gain feedback from patients, family members and partners, friends and staff; and to improve service effectiveness.

	Please Circle
1. I confirm that I have read and understood the participant information sheet (dated Sept 2011) for this evaluation, and have had the opportunity to ask questions.	Yes / No
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.	Yes / No
3. I understand that I also have the right to change my mind about participating in the study for a short period (2 weeks) after the study has concluded.	Yes / No
4. I understand that all the information I provide will be treated in confidence, and stored securely, that my responses will be anonymised, and that only myself and the research team will have access to the data.	Yes / No
5. I understand that if I indicate that I may harm myself or others, or that someone may harm me, other people may need to be informed.	Yes / No
6. I agree to be audio recorded, and for anonymised quotes to be used for research and publication purposes.	Yes / No
7. I agree to take part in this evaluation project.	Yes / No

Name of Participant	Date	Signature
Name of parent/carer if applicable	Date	Signature
Name of Researcher	Date	Signature

INTERVIEW QUESTIONS FOR YOUNG PEOPLE

Questions about the service

How did you find out about the service for TYA’s at Leeds?
(Was it seamless, were you referred to Leeds automatically, any difficulties or problems?)

What was it like being on the ward? (sleeping/eating/privacy/distractions/activities)

Do you have any experience of being on another children’s/adult’s ward? Does the TYA ward differ in any way?

Did any of your friends come to visit you? How easy was it for them to get here?

Did your friends understand about your diagnosis?

Did you make any friends on the ward?
(If yes) Do you stay in touch?

Which services did you use?
(Show relevant service map)

(If not already discussed in previous response) Were you allocated a key- worker or liaison person?

(If allocated) What was it like having a key-worker?

Do you know if anyone spoke to your school/college/university or place of employment on your behalf?

What kind of information were you given about your diagnosis and treatment?

(At what point was information received? Who gave it to you? Verbal, written, followed up in writing?)

Did you understand all the information you were given? If not, did you know where to go, or who to ask for help?

[Same questions for fertility if not mentioned]

Were you involved in decisions about your treatment?

Were you offered a clinical trial?

What was finishing treatment like?

General Questions

Do you think you benefited at all by using the TYA service at Leeds?

Are there any aspects of the service that you find/found particularly useful?

Are there any aspects of the service that you find/found less useful?

Would you make any changes to the service?

Would you recommend this service to others?

Is there anything else that you would like to say, that you’ve not already mentioned?

QUESTIONS FOR CARERS / FAMILY MEMBERS / PARTNERS

Questions about the TYA Service

How did you find out about the service for TYA's at Leeds?
(Was it seamless, were you referred to Leeds automatically, any difficulties or problems?)

Which services did you and/or your (son/daughter/partner) use?
(Show relevant service map)

(If not already discussed in previous response) Were you allocated a key- worker or liaison person?

(If allocated) What was it like having a key-worker?

Did you receive information about the diagnosis and treatment? [Including fertility]

Were you and your (son/daughter/partner) involved in decisions about your treatment?

Were you offered a clinical trial?

What was finishing treatment like?

Questions about carer's health and social needs

It can be very emotionally and physically demanding caring for a young person with cancer, how did you deal with that?

Did you receive any support the TYA service team?

How did you cope financially?

General questions

Do you think there were any benefits to using the service at Leeds?

Are there any parts of the service that you found particularly useful?

Are there any aspects of the service that you found less useful?

Would you make any changes to this service?

Would you recommend this service to others?

Is there anything else that you would like to say, that you've not already mentioned?

QUESTIONS FOR HEALTH & ALLIED HEALTH PROFESSIONALS

Questions about the service:

From your perspective, has the service been effective or successful? Can you share specific examples?

Does the service make progress towards the desired outcomes? (do you know what the desired outcomes are?)

Are there any needs that are specific to TYA's compared to those of younger children or adults?

What skills do you think are needed by staff caring for TYA's?

Ideally, at what age do you think young people should remain on ward 78/79? And what age do you think young people should be on, or transferred to ward 94?

Have you encountered any challenges or concerns about this service? If yes, can you describe them?

Can you talk about how the team functions as a whole?

How do you support each other as a team?

Questions about parent/carer health and social needs:

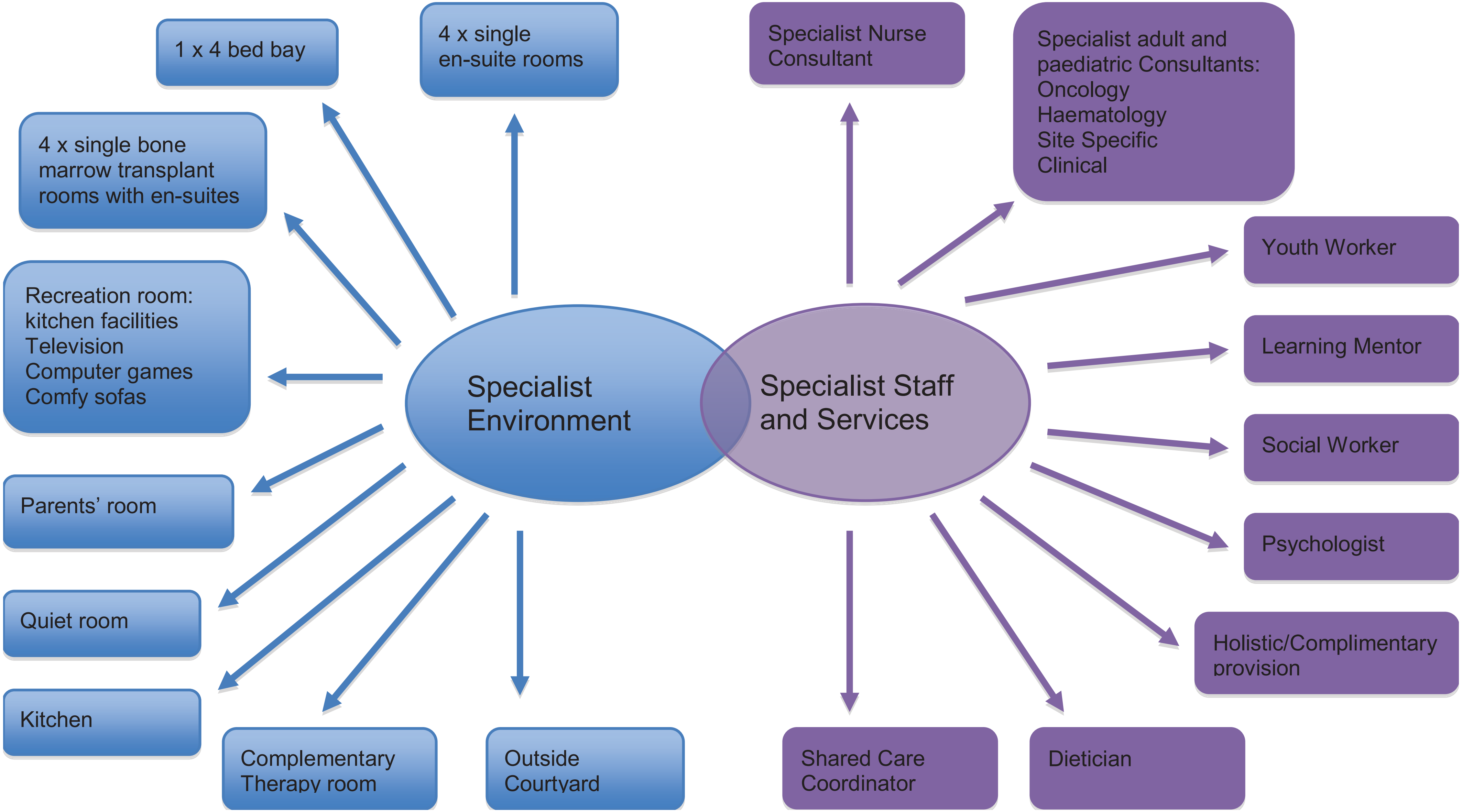
How do you assess parent/carer's physical, emotional and social health needs, and if you identified a problem what would you do? Can you share an example?

General questions

Would you change anything about the service?

Is there anything else that you would like to say, that you've not already mentioned?

LEEDS GENERAL INFIRMARY, SPECIALIST UNIT FOR TEENAGERS – AGE 13 TO 16 YEARS



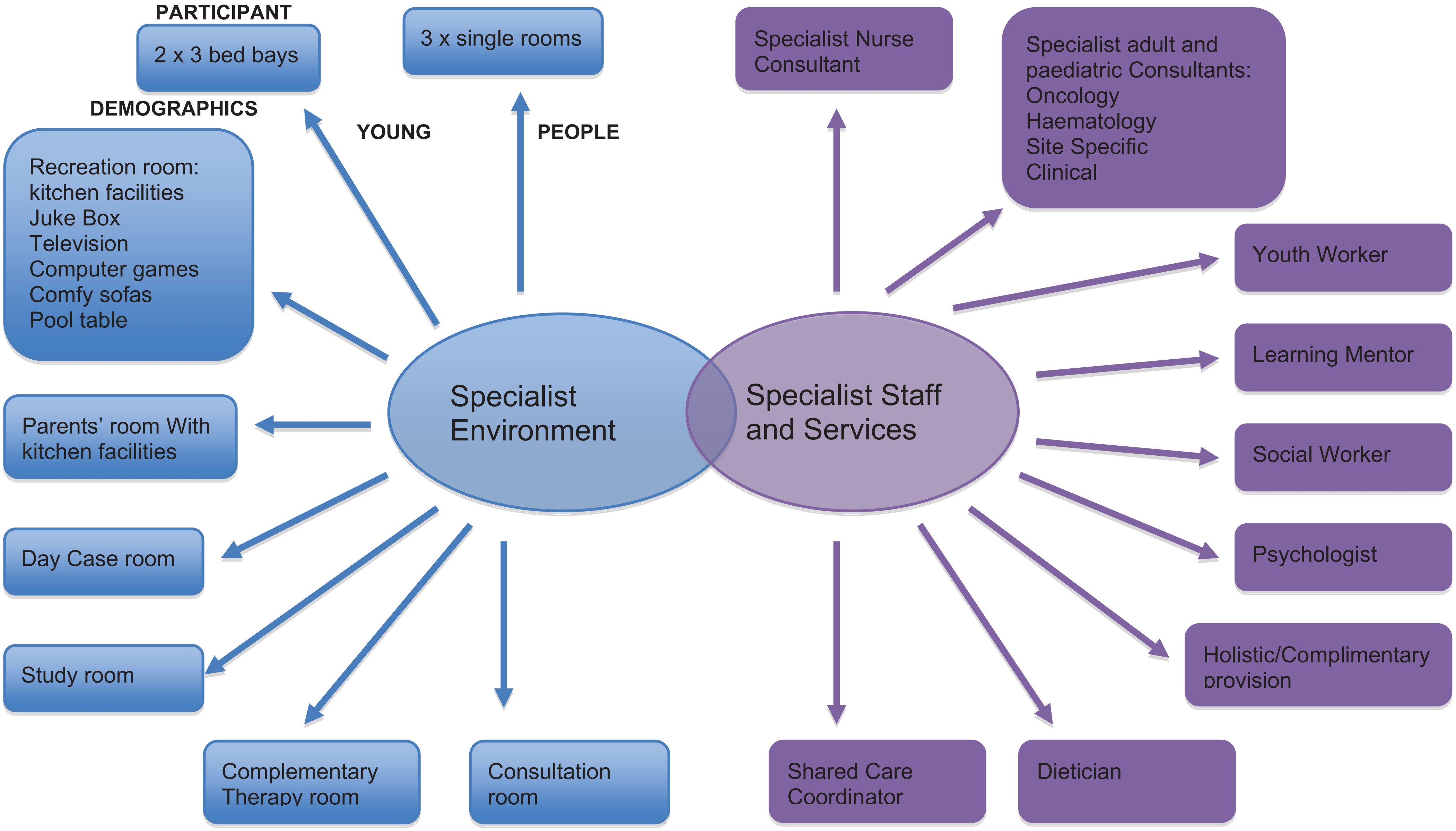
Specialist Environment

- 1 x 4 bed bay
- 4 x single en-suite rooms
- 4 x single bone marrow transplant rooms with en-suites
- Recreation room:
  kitchen facilities
  Television
  Computer games
  Comfy sofas
- Parents' room
- Quiet room
- Kitchen
- Complementary Therapy room
- Outside Courtyard

Specialist Staff and Services

- Specialist Nurse Consultant
- Specialist adult and paediatric Consultants:
  Oncology
  Haematology
  Site Specific
  Clinical
- Youth Worker
- Learning Mentor
- Social Worker
- Psychologist
- Holistic/Complimentary provision
- Dietician
- Shared Care Coordinator

LEEDS ST JAMES' UNIVERSITY HOSPITAL, SPECIALIST UNIT FOR YOUNG ADULTS – AGE 17 TO 24 YEARS



PARTICIPANT DEMOGRAPHICS

YOUNG PEOPLE

Specialist Environment

- 2 x 3 bed bays
- 3 x single rooms
- Recreation room:
  kitchen facilities
  Juke Box
  Television
  Computer games
  Comfy sofas
  Pool table
- Parents' room With kitchen facilities
- Day Case room
- Study room
- Complementary Therapy room
- Consultation room

Specialist Staff and Services

- Specialist Nurse Consultant
- Specialist adult and paediatric Consultants:
  Oncology
  Haematology
  Site Specific
  Clinical
- Youth Worker
- Learning Mentor
- Social Worker
- Psychologist
- Holistic/Complimentary provision
- Dietician
- Shared Care Coordinator

APPENDIX II PARTICIPANT DEMOGRAPHICS

Name	Ethnicity	Gender	Age	Age at Diag.	In patient + ward	Other tx centres	R/ship	Siblings	Ed. at Tx	Ed. current	Work status at Tx	Work status current	Distance From Leeds	Mode of travel
Gemma	White British	Female	20	18	Yes 94	Yes	Single	Sister 30	FE	FE	Part time	Part time	12 miles	Car
Natasha	White British	Female	20	18	**No** 79	Yes	Single	Sister 15	HE	HE			14 miles	Parent's + own Car
Poppy	British Pakistani	Female	22	20	Yes 94	No	Single	Sister 32 3 broths 25,29,34			Emp. Full time	Emp. Full time	4 miles	Car
Rebecca	White British	Female	19	14	Yes 10/10T	No	Single	None	Comp Ed	FE			12 miles	Parent's Car
Zoe	White British	Female	18	12	Yes 10/10T	No	Single	Sister 28 2 Broths 22, 24.	Comp Ed			Not emp. or in Ed, nor on benefits	3 miles	Parent's car
Alex	White British	Male	16	10	Yes 10T	Yes	Single	Broth 13	Comp Ed	FE			60 miles	Parent's car
Harry	White British	Male	16	13	Yes 10T	Yes	Single		Comp Ed	FE			60 miles	Hospital Transport
James	White British	Male	15	14	Yes 78	Yes	Single	Sister 12	Comp Ed	Comp Ed			24 miles	Parent's car
Joe	White British	Male	24	19	Yes 94	No	Ptnr				Un-employed	Self employed	8 miles	Public transport
Jordan	White British	Male	21	18	Yes 10T	No	Single				Un-employed	Self employed	75 miles	Own car
Kieran	White British	Male	16	13	Yes 10T	No	Single	Broth 14 Sister 12	Comp Ed	Comp Ed			12 miles	Parent's car
Matthew	White British	Male	25	24	Yes 94	Yes	Single				Full time	Full time	5 miles	Taxi & own car
Michael	White British	Male	23	22	Yes 94	No	Ptnr	None	HE	HE			3 / 200 miles	Public transport
Ryan	White British	Male	20	19	**No** 94	No	Single		FE			Self employed	10	Own car

Young Person Demographics

Gender: 5 young women, 9 young men.

Ethnicity: 13 British white, 1 British Pakistani.

Current Age, women: All aged between 18 and 22. Average age 20.

Current Age, men: All aged between 15 and 25. 4 aged 15 and 16, 5 aged between 20 and 25 average age 19½

Age at Diagnosis/Start of Treatment: Ranged from 10 to 24, with average overall age at diagnosis being 16½ for both young men and women.

Inpatient/outpatient: All but two of the young people were inpatients. Two of the young women were inpatients on Ward 94 and two stayed on both 10 and 10T Wards. Of the young men, four were inpatients on Ward 10T, one stayed on Ward 78 and three were inpatients on Ward 94. The remaining two young people, consisting of one young woman and one young man were outpatients on Ward 79 and Ward 94 respectively.

Other Treatment Centres: Five young people (two young women and three young men) attended other hospitals for treatment.

Relationship status: Two young men were in heterosexual, long term relationships at the time of diagnosis, and remained in those relationships at the time of interview.

Education: At the time of diagnosis, ten of the young people were in some form of education. Six young people were in compulsory education - four young men aged between 10 and 14, and two young women aged 12 and 14. Of these six, two remain in compulsory education and three are now in further education, with one young woman also working part-time. Of the remaining young people, one young man and one young woman were in further education, with the young woman remaining in further education at the time of interview. Similarly, one young man and one young woman were in higher education at the time of diagnosis, however, at the time of interview both were still in higher education.

Employment: At the time of diagnosis three young people were in employment and two were unemployed. Of these, one young man was employed full time, with one young woman in part-time, employment and the other in full-time employment. At the time of interview, one young man and one young woman were in full-time employment, one young woman was in part-time employment, three young men were self-employed, and one young woman was neither employed, unemployed, nor in education (NB: the status of 'unemployed' is defined by the young person claiming job-seekers' allowance or similar).

Mode of Travel and distance: The distance travelled to Leeds Primary Treatment Centre (PTC) ranged from three miles to 75 miles, with one young man now travelling 200 miles to attend his follow on treatment. In all, four young people travelled five miles and under to reach the PTC. Six young people travelled between 6 and fifteen miles to reach the PTC, one young person travelled between sixteen and twenty four miles, and three young people travelled more than fifty miles - two at approximately sixty miles, and one at seventy five miles. Most young people (eleven) travelled to the PTC by private transport in either their own or their parent's car, although one young man also used taxis at certain points in his treatment. Of the remainder, one young man used hospital transport and two young men used public transport.

PARENTS/CARERS

Name	Ethnicity	Gender	Age	Marital status	Children other than TYAC	Distance from Leeds	Mode of travel
Jennifer (mother of Gemma: 18)	White British	Female	49	Married	Step daughter: 30	20 miles	Car
Kate (mother of: daughter 22)	White British	Female	46	Married	Son: 17 Daughter: 19	6 miles	Car
Lauren (mother of Kieran: 16)	White British	Female	38	Married	Son: 14 Daughter: 12	12 miles	Car
Lucy (partner of Joe 24)	White British	Female	22	Long term Relationship	Son: 2 months	8 miles	Public transport
Megan (mother of Alex:16)	White British	Female	41	Married	Son: 13	60 miles	Car
Stephanie (partner of Michael: 23)	White British	Female	23	Long term relationship	None	3 miles	Public transport
Cameron (father of Alex: 16)	White British	Male	45	Married	Son: 13	60 miles	Car
William (father of James: 15)	White British	Male	41	Married	Daughter: 12	25 miles	Car

Eight parents and carers were interviewed, six women and two men, all identified as White British, and all were in long-term relationships. All parents were in their late thirties and forties, and the two carers were in their early twenties. All parents had other children in addition to their child who had experienced cancer. Of the carers, one had no children, while one had recently had a child with her partner who had experienced cancer. With regard to transport, the two carers used public transport to reach the PTC, and both travelled eight miles or less. All parents accessed the PTC through private transport and travelled between six and sixty miles.

STAFF

Ethnicity	Gender	Age	Married or long-term r/ship	Children Young=under 13 TYA = 13-25 Older = over 25	Usual place of work
White British	Female	20-29	Yes		St James’
White British	Female	20-29	No		LGI
White British	Female	20-29	No		LGI
White British	Female	30-39	Yes	2 x young	St James’/LGI
White British	Female	30-39	Yes		St James’/LGI
White British	Female	30-39	Yes	1 x young	LGI
White British	Female	40-49	Yes	1 x young 1 x TYA	LGI
White British	Female	40-49	Yes	1 x TYA	LGI
White British	Female	40-49	No	1 x TYA 1 x older	St James’
White British	Female	40-49	Yes	2 x young	St James’/LGI
White British	Female	40-49	Yes	2 x young	St James’/LGI
White British	Female	40-49	Yes	3 x young	-
White British	Female	40-49	Yes		St James’/LGI
White British	Female	50-59	Yes	1 x older	LGI
White British	Female	50-59	Yes	2 x TYA 2 x older	LGI
White British	Male	40-65	Yes		LGI
White British	Male	40-65	Yes	2 x TYA	LGI
White British	Male	40-65	Yes	2 x young	St James’
White British	Male	40-65	Yes	2 x older	St James’/LGI
White British	Male	40-65	Yes	1 x younger 3 x older	St James’/LGI

In total, twenty members of staff were interviewed, fifteen women and five men, all identifying as White British. The White British bias, is rather startling, but reflects the age and ethnicity workforce profile of the National Health Service in Yorkshire and the Humber (Working for Health, www.yorksandhumber.nhs.uk/document.php?o=701). Similarly, the gender sample reflects the predominant gender bias found in most caring professions. The average age of participants was in the mid forties. Fourteen members of staff had children. The children’s ages were mixed, with five participants having at least one child in the TYA range (13-24), and five having at least one older child over the age of 25. In addition, six participants had only younger children under 13.

The job roles of participants consisted of senior level staff and consultants, allied health professionals, and nursing staff. The nursing staff included ward staff, clinical nurse specialists, team leaders and ward managers.