

Project report submitted in partial fulfilment for the
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An Evaluation of Age – Appropriate Care for Teenagers and Young Adults with Cancer in Leeds Teaching Hospitals Trust, Paying Particular Attention to In-Patient Physical Environment and Peer Support

Olivia Moran, 200375608
Natasha Valiallah, 200381287

Supervised by:

Dr Dan Stark

Dr Bob Phillips



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Abbreviations

DoH	Department of Health
LGI	Leeds General Infirmary
LTHT	Leeds Teaching Hospitals Trust
M	Mean
NICE	National Institute of Clinical Excellence
NSF	National Service Framework
SD	Standard deviation
SJUH	St James' University Hospital
TCT	Teenage Cancer Trust
TYA	Teenagers and young adults [with cancer]
TYAC	Teenage and Young Adults with Cancer organisation
UK	United Kingdom

Introduction

Cancer is the leading cause of disease-related death in teenagers and young adults (TYAs), under the age of 24 years¹. Every day in the UK, six TYAs are diagnosed with cancer; this is approximately 2,500 per year and numbers are significantly rising^{1, 2}. Despite increased concern expressed by healthcare organisations, there has been very little improvement in the prognosis of this age group over the past two decades, with five year survival rates falling behind that of children and adults³. This illustrates the need for specialist, age-appropriate care for teenagers and young adults with cancer.

Adolescence represents a time of significant physical and social changes⁴. Individuals are growing, learning and on the brink of independence, whilst heavily dependent on their peers. During this critical period, a cancer diagnosis can have a major impact on their psychological and physical development, further demonstrating the need for age-appropriate care⁴. It remains important that throughout the cancer journey, the young person has the opportunity to continue to live life as normal as possible to achieve developmental tasks and milestones that occur during this stage of life⁵.

The Teenage Cancer Trust (TCT) is the only charity in the UK which is dedicated to the care of young people with cancer, improving their quality of life and chances of survival⁶. The TCT brings TYAs together, allowing them to be treated holistically in specialist units. TCT units in Leeds consist of Ward 33 at Leeds General Infirmary (LGI) which takes TYAs aged 13-18 years, and Ward 94 at St James University Hospital (SJUH) which provides service to TYAs aged 19-24 years. The TCT joins and bridges the gap between paediatric and adult cancer care to address their age specific needs.

The Department of Health (DoH) states that all organisations providing health and social care are required to undertake evaluations of service⁷. This involves seeking the views and wishes of patients or service users, acting on these views and involving local people in decision making. The aim of this project was to evaluate the quality of in-patient services provided for teenagers and young adults with cancer in Leeds, in two areas thought to mediate their psychosocial wellbeing⁸: physical environment and the facilitation of peer support. This would allow us to determine whether we are meeting the psychosocial needs of TYAs in these areas. An additional aim was to identify possible strategies that could be implemented to overcome any potential weaknesses in the service provided, that may be demonstrated in the results.

Background

Physical Environment

Staying as an in-patient in hospital can be a stressful experience; removed from daily routine and often no one to talk to. An adolescent on a paediatric or adult ward can feel isolated without the company of people their own age and age-appropriate facilities to occupy them^{9, 10}. This can affect their psychosocial well-being and impede their treatment¹¹. Therefore, young people and their family and peers may benefit from a specific ward environment^{9, 12, 13}. NICE guidelines recommend treating TYAs on a separate age-appropriate ward, reinforced by the TCT and Teenage and Young Adults with Cancer's (TYAC) 'Blueprint of Care' which suggest features essential to such units¹⁴. The fundamental aim of specialist TCT wards is to achieve a 'home from home' environment. The facilities, such as the day room, pool table and arts and crafts, create a relaxed and friendly environment, thus contributing to an atmosphere of normality, helping to put the young person at ease¹⁰. It has also been recommended that there should be dedicated areas for relaxation¹⁴.

Mulhall et al (2004) evaluated an adolescent cancer unit and addressed the way in which physical layout and facilities of the ward shape the experience of the adolescents¹⁰. The importance of privacy on the cancer ward was highlighted, in addition to privacy requirements altering with time and circumstances¹⁰. Privacy is promoted on TCT units by smaller wards, nearby bathroom facilities, and the incorporation of locks and curtains providing the option of additional privacy. Achieving the desired level of privacy is vital for TYAs as it helps development of individuality and protects personal autonomy. Further, TYAs are more susceptible to a negative body image and sufficient privacy can aid coping with changes in appearance^{11, 15}.

A comparative study found TYAs treated on paediatric or adult units were dissatisfied with privacy levels, in contrast to those on TCT wards⁹. This suggests privacy is facilitated on specialist adolescent cancer wards, but further study is necessary to see if it is facilitated on other TCT units and to identify which aspects of the units aid privacy needs⁹. Research has begun to reveal how adequate privacy on specialist units benefit the young person. However, as this particular aspect of care has not been explored fully, research is needed to determine how well the privacy needs of TYAs are being met and if there is room for improvement.

Peer Support

The support and emotional needs of adolescents have been highlighted since the 1950s¹⁶. Subsequent research has found emotional support to be essential to patients for undergoing treatment^{17, 18}. Consequently, NICE guidelines documented the need for adolescents' psychological support¹⁹. Recent study by Goodall et al (2012) concluded emotional support from peers as the most valued type of support by TYAs²⁰. Further evidence notes the importance of friendships and identifies peer support as a coping mechanism for dealing with cancer. Research has demonstrated that higher coping scores are attributed to greater levels of social support^{10, 21}.

Young people with cancer greatly benefit from a peer support network outside of hospital. Adolescents significantly value friends who they can rely on during treatment, who knew the adolescent prior to diagnosis and continues to treat them as before¹³. An outside peer support network can re-establish a sense of normality, keep them updated on life outside of hospital, act as a mechanism of resilience and provide them with a constant despite inevitable changes they will undergo⁸. Peers also play a significant role on an adolescent's ability to renegotiate their social circle after treatment¹⁵. These factors combined demonstrate the need for continued contact throughout their cancer journey, and it is important to facilitate their connection whilst the adolescent is in hospital. This can be achieved by liberal visiting hours and communicating with peers over phone, internet and social networks, which are provided by specialist TYA cancer units.

Research has established that a sense of shared understanding is essential to TYAs and can only be achieved by similar experience of those met within hospital¹⁰. They are able to talk freely about cancer related issues and there is nothing they cannot discuss; they can socialise and be themselves¹⁰. For those undergoing treatment, peers can be an inspiration, and similarly those who have finished treatment can inspire others. Dedicated teenage and young adult cancer units bring TYAs together, and facilitate contact with other TYAs with cancer, who are able to offer friendship, and provide support and insight. Smith et al (2007) conducted a large scale study and found the majority of TYAs preferred being treated on specialist units²². Further, many TYAs had interest in joining online chat groups with other TYAs, and those with no experience of being with other TYAs sought peer contact by other means, supporting the concept of needing contact with other young people with cancer^{22, 23}.

Methods

Participants

The project was conducted in the two TCT specialist units at LGI and SJUH, of the Leeds Teaching Hospital Trust (LTHT). Participants included teenagers and young adults with cancer, aged 13-24 years, who stayed as in-patients on either unit, between the time of December 2012 and January 2013. TYAs on the ward during selected times of data collection were invited to participate forming an opportunistic sample ($n = 22$). Inclusion criteria consisted of those deemed well enough to undertake interview, as judged by senior staff. No exclusions were made on pre-existing co-morbidities, reason for admission or type of cancer. Informed consent was gained from the TYAs prior to interviewing and ethical approval was not required.

Data Collection

A purpose-designed proforma was created based upon relevant literature and informal interviews conducted with specialist doctors, nurses and youth support co-ordinators. The proforma was composed of open, closed and categorical questions, in addition to Likert scales²⁴, and was used to guide semi-structured interviews carried out with the TYAs (Appendix 1). The two authors took responsibility for interviewing one age group at the associated hospital. The interviews aimed to elicit patient opinions of the specialist ward in their own words. Questions included 'Do you feel you have enough privacy on the ward?' and 'How do you feel about having friends over?'. The duration of interviews varied and all responses were recorded on the proforma throughout. Data was collated in a database for analysis (Appendix 2).

Data Analysis

Quantitative data was obtained from the use of closed questions, categorical questions and Likert scales and was analysed using SPSS statistical software (version 21.0 for Mac, SPSS Incorporated®, Chicago, USA). Percentage values and margins were calculated. Student's t -tests were performed to explore any statistical differences between data gathered at the separate units. Data was considered to be statistically significant if $p < 0.05$.

Qualitative data was gained from open questions and interpreted using thematic analysis according to Braun and Clarke (2006) (Figure 1)²⁵. Each researcher read the completed proformas of 'their' interviews to gain an overall impression of the data. For each qualitative question, data was re-read in depth and reduced to codes. The codes for each question were collated and were sorted into themes. Potential themes were discussed by both

researchers, so proficient lists were created. Each researcher reviewed the themes for their own data, but came together when defining and naming themes to ensure a universal understanding of the theme that could be applied across the data for both units.

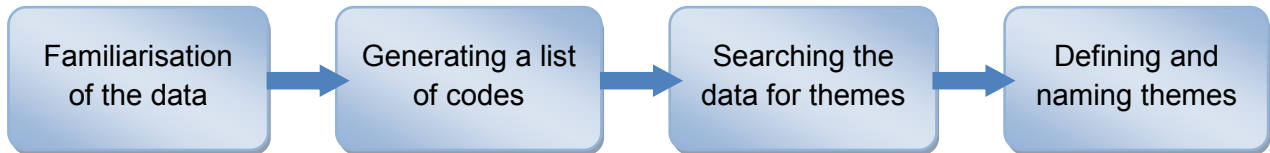


Figure 1 – Stages of Thematic Analysis

Flow chart demonstrating the stages of thematic analysis as described by Braun and Clarke (2006)²⁶

Inter-rater variation determined the consistency in qualitative data analysis between both researchers. Five open questions requiring thematic analysis were selected at random for testing using Cohen’s Kappa²⁶. Prior to this process, it was ensured that each researcher had read their own sets of data only, to reduce unreliability. For the selected questions, each researcher read the proformas of the other, and underwent qualitative data analysis across both sites. Once the data for the chosen questions had been analysed by both researchers, it was possible to identify agreements and disagreements in the analysis. This was inserted into contingency tables respectively to calculate Kappa for each question.

Results

This study focused on two dimensions that allowed for in-depth investigation; four subcategories were further identified (Table 1). The findings reveal what the patients valued in the physical environment and the facilitation of peer support in the unit and why. Adequacy, preferences, experiences and improvements were elucidated. Inter-rater variation was shown to be good or very good by classification of Cohen’s Kappa values (Appendix 3).

Aspects of Hospital Life Investigated	
Physical Environment:	Peer support:
Additional areas and facilities	Activities
Privacy	Peers outside hospital
Staff	Peers within hospital
Well-being	Well-being

Table 1 – Aspects of Hospital Life Investigated

Table displaying the categories of hospital life identified for investigation.

Sample demographics

The opportunistic sample was mainly female and from the LGI site ($n = 14/22$). One participant diagnosed with Asperger's syndrome was excluded as the syndrome is characterized by an impairment in social interaction²⁷. As the sample was small it was decided her 'anomalous' responses should be excluded from analysis, to reduce unreliability of results. However, the authors acknowledge the importance of her experience on the ward. Table 2 displays participant demographic details.

Sample Demographics	Value of Measure
Occupation:	
School	8 (38.1%)
Work	4 (19.0%)
Sixth Form	5 (23.8%)
Student	3 (14.3%)
Unemployed	1 (4.8%)
Time since Diagnosis (weeks) (M, SD)	33.5 (37.9)
Length of Stay (days) (M, SD)	36.2 (81.7)
Distance Travelled to Hospital (miles) (M, SD)	22.7 (16.5)

Table 2 – Participant Demographics

Table displaying participant demographics from both the LGI and SJUH TCT units (13-24 years). Values include the number of patients and their associated percentages, and values of time and distance with the mean (M), and standard deviation (SD).

Physical Environment

Four (18%) patients interviewed were experiencing the TCT ward for the first time. Ten patients (47.6%) who had spent time on the TCT ward and a paediatric ward found that the TCT ward was 'much quieter with lots of facilities'. Remarks also focused on the age-appropriateness of the TCT ward. One patient said that 'knowing the staff on the ward added an extra sense of comfort'. Four patients (19%) who had experienced the TCT ward and an adult ward again focused on the facilities and age-appropriate environment of the TCT ward. There was an appreciation for being with others their age, 'not having to be with older people that don't understand you as much is better...many of the older patients were closer to death which made me feel uneasy'.

Additional areas and facilities

Figure 2 shows additional areas of the ward used by TYAs. Almost all of those interviewed used the recreational room for social purposes, and a third used the quiet room for a peaceful environment, to reflect or for private activities like reading.

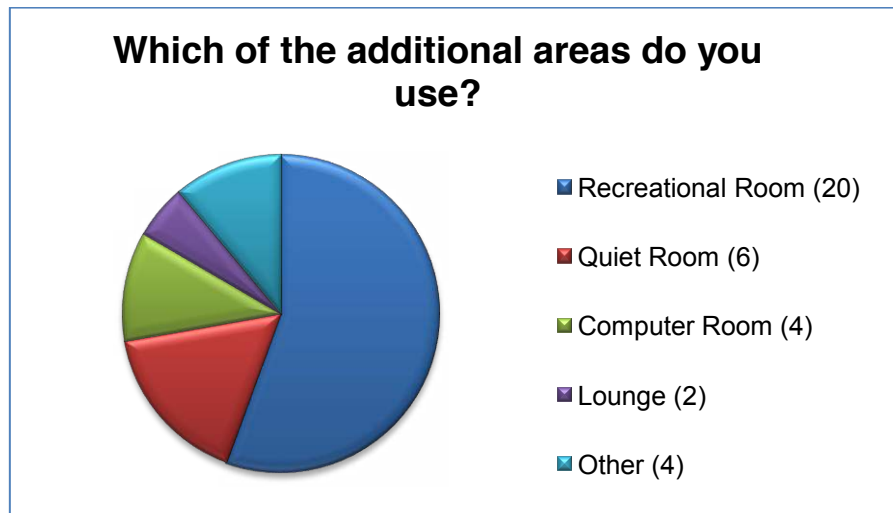


Figure 2 – Use of Additional Areas

Pie chart to show the additional areas used by TYAs at both LGI and SJUH sites.

The majority of TYAs were happy with the current facilities, such as televisions, game consoles and jukebox, which helped occupy them and contributed to a friendly, welcoming atmosphere. Some at LGI suggested more games consoles, musical instruments, and headphones for the televisions to further enhance facilities. Those at SJUH thought televisions in bays would improve their stay, a privilege that is only available in side rooms. The most common suggestion for improvement was fixing the weak or non-existent Wi-Fi on the wards; one TYA remarked, 'it would help me stay in contact with my friends'.

Privacy

Patients generally felt that they had adequate privacy on the ward. Only five (23.8%) stated privacy was adequate some of the time, commenting they lacked privacy when staying on a bay; private or confidential discussions with family or staff have to be held quietly, especially when 'too many people are coming in and out'. It was felt that doctors were often not sensitive to this need. Further, 14.3% of those interviewed felt there was a lack of structural barriers.

Patients from SJUH statistically significantly preference for single sex accommodation whilst those at the LGI preferred mixed sex ($t(19) = 4.83, p < 0.001$; Student's *t*-test). At SJUH

reasons such as dressing and modesty were given. One female patient preferred a single sex area because she felt 'girls understand each other more at particular times'. Those at LGI felt was 'there were more people my age to socialise with on mixed bays'.

Over half (52.4%) the sample preferred to stay in a side room; a key benefit was 'the quietness at night and in the mornings for undisturbed sleep'. Additionally, side rooms allowed optimum privacy and provided a choice of when to socialise. A third (33.3%) of patients, predominantly from the LGI, had preference to stay in a bay because it was more social. Twelve patients (57.1%) had been to a side room for isolation from infection; of these, 8 (66.7%) experienced isolation, boredom and social deficit. One LGI patient described being isolated as 'feeling cut off from the world', but stated that activities could be brought to occupy her. At SJUH, some did not feel isolated as they had family visiting and regular checks from nursing staff. Another patient remarked he was 'too ill to even care'. Of those who did not feel isolated, the majority preferred being in a side room nonetheless.

Staff

All patients felt staff understood and respected their need for privacy. About 40% of the patients were comfortable talking to all staff members on the ward. However, nurses were the primary staff members that patients chose to talk to if they had concerns or required emotional support. One patient at LGI stated 'nurses understand more than doctors'.

Well-being

Over half (57.1%) of the patients on the TCT wards felt very much at ease in their ward. Seven patients (33.3%) felt somewhat at ease and two (9.5%) felt neither at ease or uneasy; 'I'm being treated for cancer and seeing others treated stops me from feeling comfortable'.

Peer Support

Activities

At least some of the activities provided by TCT wards were enjoyed by 90% of the patients (Figure 3). Pizza night was the most popular, 95.2% of patients attended and viewed it as a prime opportunity to meet and interact with others on the ward. Arts and crafts (71.4% participation) were popular due to accessibility; patients are allowed to use the equipment at any time of day. Other activities such as guitar lessons or reflexology were not as regular or catered to minority tastes. Only 2 patients (9.5%) did not enjoy the activities provided; one said 'I don't really like any of the activities', the other preferred alternative activities such as watching television.

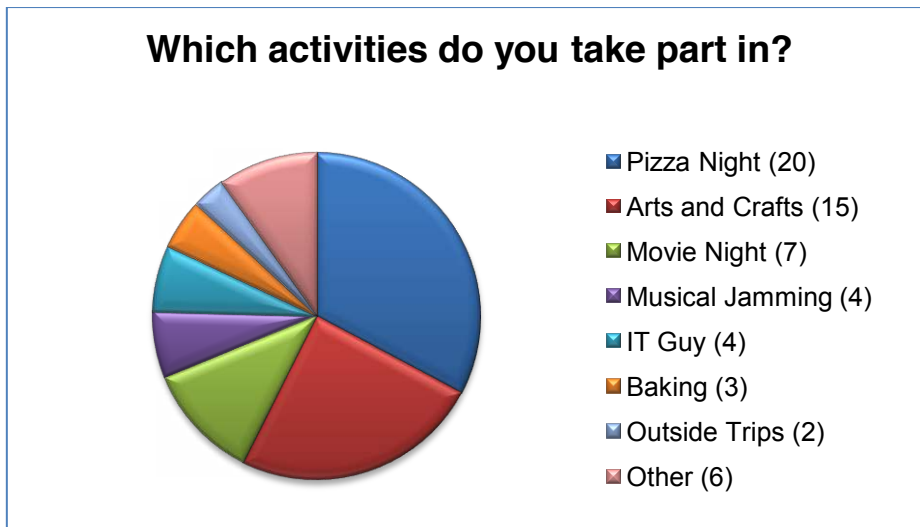


Figure 3 – Activities on the Ward

Pie chart to show the activities on the wards that TYAs took part in.

Peers outside hospital

Seventeen patients (81%) had many visitors to the ward; eighteen (85.7%) enjoyed their friends visiting. They were a source of support and entertainment, and kept them updated on life. One patient who did not have friends visiting stated ‘I feel uncomfortable...I don’t want my friends to see me sick and tired’. Travelling distances prevented some from having regular visitors, however one patient commented ‘despite having less friends visit, I would not want to be treated closer to my home if it meant being on any other ward’.

There was incredibly positive feedback on the long visiting hours; their flexibility provided the opportunity to see more guests for longer. One patient commented that ‘visiting hours are really important, I can feel down at any point of the day and visitors cheer me up’. Another remarked ‘you never know when you’re going to feel bad...the flexibility allows you to work around this’.

Peers within hospital

Seventeen (81%) TYAs had made new friends on the ward, some kept to their own friends that visited and one had not been on the ward long enough to meet friends. Approximately 90% of TYAs felt encouraged by staff to socialise on the ward; none of them felt pressured to do so. Figure 4 shows the variation of general sociability of TYAs, which they felt reflected how social they were on the ward.

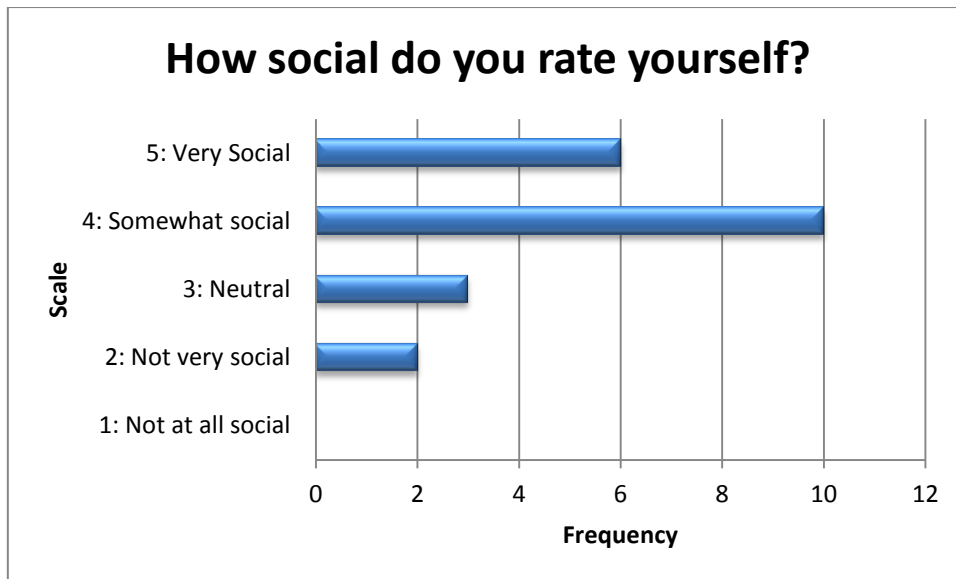


Figure 4 – Activities on the Ward

Pie chart to show the activities on the wards that TYAs took part in.

Well-being

All patients viewed having friends as either very important (76.2%) or of some importance (23.8%), reflecting their willingness to make friends on the ward and invite friends from home. Almost all patients felt very supported on the ward (85.7%), two felt somewhat supported and one felt neither unsupported nor supported.

When TYA’s were asked whether they liked to keep their social lives in and out of hospital separate, nearly 50% stated that they did not want to keep them separate, one patient commented that she ‘likes them to mix as they are all a part of her life’. Those at LGI wanting to keep their social lives separate said ‘I could tell when my friends felt uncomfortable’, another stated, ‘I have not made many friends so have no-one I want them to meet’. Some patients at SJUH wanted a distinction between their friend-groups, to be free from cancer related issues with their home friends, but on the ward with people who ‘understood’.

Most patients stated no improvements could be made to increase opportunities for socialising. At the LGI, one patient noticed there were fewer activities since the youth co-ordinator had gone on maternity leave and suggested she needed replacing. At SJUH it was suggested that activities could take place on weekends and that they would like to be told if anyone else on the ward has the same condition as them.

Discussion

This qualitative evaluation has demonstrated that participants were generally pleased with the services provided on both wards, when considering the physical environment and the facilitation of peer support.

Physical Environment

A conceptual model, used to explain the experience of TYAs, associates the importance of physical environment and facilities to psychosocial well-being⁸. Patients interviewed who were able to compare their experience with paediatric or adult wards unanimously agreed they were 'unsuitable' and 'alienating', consistent with studies that evaluated other specialist units across the country^{9, 10, 28, 29}. When considering the reasoning behind this, emphasis was placed on age-appropriate facilities and specialist staff. Additional reasons, demonstrated in a further extensive comparative study by Reynolds et al (2005), included being in the company of people the same age ($p < 0.0001$; Mann-Whitney U test) and ward noise ($p < 0.02$; Mann-Whitney U test)⁹. Although the data from this evaluation indicates differently, Reynolds et al (2005) also found TYAs were satisfied with the overall care they received, independent of the type of unit⁹. This suggests that overall care received by TYAs was approximately equal, or alternatively, a ceiling effect on patient satisfaction scales.

The division of the two TCT wards by age appears beneficial. This evaluation demonstrated younger patients had different requirements, with a trend towards being more sociable. Preference for mixed sex bays in the younger ward, allowing for increased chances of socialising, was found to be significant, and a preference for single sex bays in the older age group ($p < 0.001$; Student's t -test). This was also apparent in a large-scale study by Smith et al (2007)²⁸. Physical, biological and cognitive developments coincide with psychological and social changes as individuals progress through ages 13-24³⁰. Older patients are more 'developed', and privacy and dignity now preside over sociability as they become more concerned about their body image and sexual identity, potentially accounting for their preference for same sex bays³¹.

Privacy has been shown to aid coping with emotions such as loss, shock and sorrow³². General levels of privacy were found to be acceptable by patients in this evaluation and previous research¹⁰. Nevertheless, Mulhall et al (2001, 2004) and Smith (2007) highlight that optimising privacy on the wards appears to take a 'backseat' in comparison to other psychosocial mediators including peer support, despite being arguably as important^{10, 28, 33}. This may result from practical issues faced when facilitating privacy; for example, it is not feasible to have all patients in side rooms when staff need sufficient access to patients

in case of emergency. TYAs reported privacy was compromised in bays, in which sensitive conversations with staff, family and friends were easily overheard by others. Mulhall et al (2004) also highlighted this exact problem from opinion of staff, but without suggestion of how it may be overcome¹⁰. Staff awareness and acting on this issue may make a considerable difference.

This study has emphasised the importance of the environment allowing and adapting for personal preference throughout the illness trajectory. Some TYAs require a greater degree of privacy than others, therefore not joining in with activities should be seen as acceptable and be respected by staff. Mulhall et al (2004) provides evidence that there are specific times when a side room maybe more appropriate than a bay, for example, it can help in dealing with the reality of staying on a cancer unit on first admission¹⁰. However, this study had a small sample and lacked comparison with a non-specialised unit. Further exploration of this subject could help staff judge when it may be appropriate to move a patient from a bay to a side room for their psychological well-being.

When privacy has been excessive, for example when isolated in a side room for medical reasons, there appears to be a degree of negative affect in TYAs who were not occupied by family or checked on regularly by the nursing staff. Evidence suggests that boredom and feelings of depression and anxiety due to prolonged isolation can be detrimental to patients' psychological well-being³⁴. Although this study is not specific to TYAs, their developmental stage suggests increased susceptibility to psychological problems. Therefore, when isolation is medically necessary, particular attention should be paid to avoid this.

Peer Support

Multiple studies note the importance of encouraging friends to visit the ward^{35, 36}. The majority of participating TYAs had friends outside hospital visiting, reporting that peers were a source of support and entertainment. Consistently, Grinyer (2007) highlighted peers make TYAs feel at ease in their strange medical surroundings that they, too, may find daunting; ongoing contact also enables them to keep in touch with important things in their life³⁵. Whilst maintaining relationships is encouraged, research has demonstrated some fear being 'left behind', their friends progressed, whereas they did not, leading to feelings of isolation³⁶. This study is limited by its qualitative approach; it is unclear how consistent this theme was across the small sample.

Nearly all TYAs used phones and social networks, such as Facebook, to keep in contact with peers outside the hospital. When discussing facilities on the ward, several complaints were made about internet Wi-Fi at both sites. In an age heavily reliant upon the internet,

contact with peers is inevitably affected. This arguably reduces contact with existing peers outside the hospital, thus limiting the support they are able to provide. Further, Smith et al (2007) found many TYAs had interest in joining on-line chat groups with other teenagers with cancer; this could be hindered by Wi-Fi difficulties²⁸.

The results demonstrate the majority of TYAs made friends on the ward. Peer support was facilitated by staff encouragement and activities on the ward. The physical structure of bays provides opportunities to socialise by increasing peer contact but adversely reduces general privacy, as previously addressed¹⁰. Although an important source of support, the major downfall associated with relationships formed on the ward is the risk of witnessing relapse, disease progression or death of a peer, adding to emotional stress and anxiety. Kelly et al (2004) found some may view this as preparation while others stated they would rather endure suffering than miss the 'intimacy and security' which the unit also provides³⁷. However, these findings are based on only one interview; multiple interviews over time would improve the validity of these results.

Peer support has been shown to be crucial to adolescents²⁸. If young adults disconnect from their peer group and become dependent on parents for companionship and support, fear and unwillingness to take part in activities away from the security of their family may result, suggesting a chronic effect of the illness³⁸. The utilisation of peer support remains dependant on sociability during their illness, which varied when rated by TYAs. This variation demonstrates individual differences, that are perhaps influenced by factors such as tiredness from chemotherapy, stages of coping or even the negative ideations of peer support by some TYAs as described in this section^{32, 36, 37, 39}. Current provisions on the ward are sufficiently facilitating peer support and allow TYAs to opt in or out of activities on the ward, thus providing them with the choice of socialising to allow for differences.

Research Methods

To fully investigate the attitudes, beliefs and preferences of TYAs, it was deemed necessary to undertake a qualitative approach with some quantitative data. Whilst qualitative methods are unable to provide data about increased survival rates or discrete measures of 'quality of life', the results can meaningfully illustrate 'how things really are'^{33,40}. Although the quantitative data in this study could not provide this information, value was found by the addition of context to our findings to provide an increased understanding of results. It was learnt that qualitative research helps to bridge the gap between scientific evidence and clinical practice, reiterating why it is suitable for service evaluation.

Limitations

There are approximately 120 in-patients per year across both units, and based on time constraints, the sample number was small, limiting the application of results. There was very good consistency between two interviewers; however psychosocial interviews are determined by the flow of conversation between the interviewer and interviewee. Thus results from this study could be researcher dependant as another researcher may not elicit the same answers. Further, the ages of the interviewers were similar to the TYAs; although it may be positive that the interviewers could relate to TYAs, it is questionable whether empathy affected interviews. The findings in this project are based on one interview only and it is important to acknowledge that opinions of TYAs may change over time.

Future Work

Although it has been demonstrated TYAs are generally happy with services provided, recommendations for future work exist. An increase in sample size would be essential to ensure the results can be generalised across the majority of patients. To strengthen the methodology, a full proof interview manual would not only include the set questions on the proforma, but also specific probing phrases with definitions of positive and negative answers. Inclusion of additional perspectives from peers themselves, parents and staff may provide further insight on views of the TYAs, the TYAs themselves and to possibly identify aspects behind positive or deficient peer support networks. Lastly, it would be necessary to repeat the project in one year to ensure continuing facilitation and meeting of the psychosocial needs of TYAs in these areas.

Public Health Issues

Several DoH publications stress the importance of upholding privacy and dignity in healthcare settings, which can be achieved by eliminating mix sex wards⁴⁰⁻⁴³. TYA cancer units struggle to adhere, whereby there are not enough young people to separate them by gender. Following national policy, TYA cancer units are expected to configure beds by gender, and patients should be given a choice of a single or mixed-sex environment. Consequently, preference for a single-sex ward may compromise the place of care, and an adolescent may have to be treated age-appropriately on an alternative ward¹⁴. The National Service Framework (NSF) states that segregation by age is more important than gender⁴⁴, consistent with the preferences of TYAs on the LGI unit in this study.

The late psychological effect of cancer also requires consideration. Survivors of cancer may feel worried, scared or even possess survivor guilt. Teenagers may potentially have a long

life ahead of them; therefore, it is important for a TYA to receive sufficient emotional and social support to promote psychological wellbeing after dealing with cancer, to overcome any emotional trauma that may occur⁴⁵. This can potentially reduce their need for associated NHS resources post-cancer.

Conclusion

This evaluation has provided evidence of an appropriate and effective service in the LTHT with regards to physical environment and peer support, consistent with studies evaluating other specialist units in the UK^{10, 20, 28}.

Individuals require different levels of social activity and privacy, which can alter throughout the cancer journey. These opposing psychosocial mediators are thought to work hand-in-hand, with a good balance of both being key to psychological well-being. Privacy may even support social interaction by providing opportunities for self-assessment and realisation which can be fed back to aid better socialising^{43, 46}. It is critical that staff are able to judge and prevent any extremes that may cause detriment to a TYA on the ward.

From the results of our study, the following recommendations are proposed to improve services:

1. Make healthcare professionals more aware of privacy on ward rounds: lowering volume of voices, going to the quiet room when discussing sensitive issues,
2. Provide the choice between a side room and bay if both are available,
3. Reduce feelings of isolation when confined to side rooms for medical reasons: encouraging familial visitors, bringing activities to occupy TYAs, regular checks from nursing staff,
4. Improve facilities such as impaired Wi-Fi at both sites.

Through multi-disciplinary briefing, the recommendations can be brought to the attention of the range of healthcare professionals working on the TCT wards.

Large-scale quantitative studies, such as the recently launched BRIGHTLIGHT Study, aim to establish the real effect of specialist units on TYA's quality of life and the effect of this on their future⁴⁷. Until such longitudinal studies are published, it is imperative that regular qualitative evaluations are implemented in the short-term to ascertain the benefits of patient-led care and ensure units consistently meet the needs of TYAs to promote and maintain psychosocial well-being.

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Appendix 1: Interview Proforma



An evaluation of age-appropriate care for teenagers and young adults with cancer in LTHT, paying particular attention to peer support and physical environment: In-patient Proforma

Age: 13-18/19-24

Gender: Male/Female

Occupation: School/Sixth Form/Student/Work/Unemployed

Date of Diagnosis:

Length of Stay:

Distance travelled to hospital:

Number of previous hospital stays:

TCT - Children's ward - Adult's ward -

How do they compare?

Environment

Physical Environment	<p>1. Of the additional areas on the ward which ones do you use?</p> <p>LGI:</p> <ul style="list-style-type: none"> - Outside courtyard <input type="checkbox"/> - Recreational room <input type="checkbox"/> - Quiet room <input type="checkbox"/> - Alternative Treatment <input type="checkbox"/> <p>SJUH:</p> <ul style="list-style-type: none"> - Recreational room <input type="checkbox"/> - Computer <input type="checkbox"/> - Study room <input type="checkbox"/> - Music room <input type="checkbox"/>
	<p>2. Do you think there are enough recreational facilities on the ward? i.e. Music room, games consoles, TV, computers, DVD player, games, books, arts and crafts, jukebox.</p>
	<p>3. Any other facilities you would like to have on the ward?</p>
	<p>4. Is the ward decorated suitably for your age?</p>
	<p>5. Do you feel personal items, like photos or bedding improve your stay?</p>

Privacy	6. Do you prefer being in a side room or on a ward with other people?	
	7. Do you prefer a single sex or mixed sex area?	
	8. Have you ever had to move into a side room for medical reasons? If so, did you ever feel isolated?	
	9. Do you feel there are enough structural barriers for privacy i.e. curtains and locks on the ward?	
	10. Are you happy with your current access to washing/bathroom facilities?	
	11. Where on the ward do you feel most comfortable to have 'alone time'?	
	12. Do you feel you have enough privacy on the ward? If not why?	
	13. Which staff members do you feel most comfortable talking to?	
	Staff	14. Do you feel that the staff understand and respect your need for privacy/alone time? If no, why?

Wellbeing	15. Do you feel the ward or facility you are treated on is suitable for a person of your age?
	16. Do you feel at ease on the ward? Scale of 1-5 1 – Not at all at ease, 2 – Not really at ease, 3 – Neutral, 4 – Somewhat at ease, 5 – Very much at ease

Peer Support													
Activities	<p>1. Of the activities provided, which do you take part in?</p> <table style="width: 100%; border: none;"> <tr> <td style="width: 50%;">LGI:</td> <td style="width: 50%;">SJUH:</td> </tr> <tr> <td>- Arts and Crafts <input type="checkbox"/></td> <td>- Arts and crafts <input type="checkbox"/></td> </tr> <tr> <td>- Pizza night <input type="checkbox"/></td> <td>- Pizza night <input type="checkbox"/></td> </tr> <tr> <td>- IT Guy <input type="checkbox"/></td> <td>- Movie Night <input type="checkbox"/></td> </tr> <tr> <td>- Musical Jamming <input type="checkbox"/></td> <td>- Musical Jamming <input type="checkbox"/></td> </tr> <tr> <td>- Other: _____ <input type="checkbox"/></td> <td>- Other: _____ <input type="checkbox"/></td> </tr> </table>	LGI:	SJUH:	- Arts and Crafts <input type="checkbox"/>	- Arts and crafts <input type="checkbox"/>	- Pizza night <input type="checkbox"/>	- Pizza night <input type="checkbox"/>	- IT Guy <input type="checkbox"/>	- Movie Night <input type="checkbox"/>	- Musical Jamming <input type="checkbox"/>	- Musical Jamming <input type="checkbox"/>	- Other: _____ <input type="checkbox"/>	- Other: _____ <input type="checkbox"/>
	LGI:	SJUH:											
	- Arts and Crafts <input type="checkbox"/>	- Arts and crafts <input type="checkbox"/>											
- Pizza night <input type="checkbox"/>	- Pizza night <input type="checkbox"/>												
- IT Guy <input type="checkbox"/>	- Movie Night <input type="checkbox"/>												
- Musical Jamming <input type="checkbox"/>	- Musical Jamming <input type="checkbox"/>												
- Other: _____ <input type="checkbox"/>	- Other: _____ <input type="checkbox"/>												
2. Do you enjoy the activities provided on the wards?													
3. Do friends/siblings join in with any activities? If not why?													
Peers Outside Hospital	4. Do you have many visitors?												
	5. Do you invite siblings or friends from outside to the ward?												
	6. Do you like having your friends come and visit?												

Peers Within Hospital	7. How do you feel about having friends over?
	8. Do you ever have friends or siblings staying overnight?
	9. Do your friends/siblings take advantage of the long visiting hours?
	10. What do you think of long visiting hours?
	11. Do you use your phone/computer on the ward to keep in touch with friends?
	12. Do you use social networks to socialize whilst in hospital? Which social networks do you use?
	13. Have you made new friends on the ward?
	14. Are you encouraged to socialize with other people your age on the ward?
	15. How social would you rate yourself as being? Scale of 1-5
	1 – Not at all at social, 2 – Not very social, 3 – Neutral, 4 – Somewhat social, 5 – Very social

16. How important is having friends to you? Scale of 1-5

1 – Not at all at important, 2 – Not very important, 3 – Neutral, 4 – Somewhat important, 5 – Very important

17. How supported do you feel? Scale of 1-5

1 – Not at all supported, 2 – Not very supported, 3 – Neutral, 4 – Somewhat supported, 5 – Very supported

18. Do you prefer keeping your social life outside of hospital separate to your social life in hospital?**19. Do you feel that there are sufficient opportunities for socializing? If not, why?****20. Do you ever find that there are too many opportunities to socialize?****21. Are there any improvements that can be made to allow you to socialize more?**

Appendix 2: Service Evaluation Database

22 patients were interviewed and data was inserted into the database for analysis

The patient interviewed but excluded from the study was highlighted in red so data was not included in the analysis

The headings of columns stated the number of the patient and the hospital

	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T	U	V
				Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8	Patient 9	Patient 10	Patient 11	Patient 12	Patient 13	Patient 14	Patient 15	Patient 16	Patient 17	Patient 18	Patient 19
				LGI	LGI	LGI	LGI	LGI	LGI	LGI	LGI	LGI	LGI	LGI	LGI	LGI	LGI	SJUH	SJUH	SJUH	SJUH	SJUH
				Age Range	13-18	13-18	13-18	13-18	13-18	13-18	13-18	13-18	13-18	13-18	13-18	13-18	13-18	19-24	19-24	19-24	19-24	19-24
				Gender	F	M	F	M	F	M	M	F	F	M	F	M	F	M	M	M	M	F
				Occupation	School	School	Sixth Form	Sixth Form	School	School	School	School	Sixth Form	School	Sixth Form	School	Sixth Form	Work	Student	Student	Unemployed	Work
				Date of Diagnosis	22.3.12	???.3.11	17.2.12	15.12.12	11.1.11	26.10.12	10.12.12	???.3.12	???.03.11	24.11.12	7.9.12	???.10.12	???.06.12	06.07.11	???.06.12	01.11.12	10.08.12	07.12.12
				Length of Stay	5 days	1 year?	4 days	3 weeks	1 day	3 days	1 week	4 days	4 months	1 day	3.5 months	3 days	4 weeks	3 days	3 days	4-5 weeks	2 days	8 weeks
				Distance to hospital	30 miles	5 miles	12 miles	7 miles	67 miles	60 miles	20 miles	25 miles	21 miles	10 miles	19 miles	38 miles	20 miles	19 miles	4 miles	25 miles	13 miles	20 miles
				No of prev hosp stays	TCT 14, Child	TCT 3	TCT 8, Child	TCT 1	TCT 4, Child	TCT 8, Child	TCT 3	TCT 18, Child	TCT 2	TCT 1, Child	TCT 20, Child	TCT 9, Child	TCT 10, Child	0	TCT-9 (first)	TCT-1, CW-	TCT-11	Adult ward-
				How do they compare?	TCT quieter	N/A	Whole enviro	N/A	TCT has be	TCT know w	N/A	TCT ward is	TCT was be	N/A	TCT is incon	TCT was be	TCT is much	N/A	TCT is welc	more social	N/A	more facilit
				Additional Areas in use?	Recreational	Recreational	Recreational	Recreational	Recreational	Recreational	Recreational	Recreational	Outside cour	Recreational	Recreational	Quiet room	Recreational	Recreational	Recreational	Recreational	Recreational	Recreational
				Are there enough facilities?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
				Any other facilities?		More beds	N	N	N	N	N	Games cons	N	More music	Games cons	N	N	Headphones			TV in the bays	N
				Ward decorated suitably?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
				Personal items?	Y	Y	Y	Y	Y - for long	Y	Y	Y - more con	Y	Y	Y	Y	Y	Y	Y	Y - I want to	Not to my ta	Y
				Side room/bay?	Bay	Either - does	Side room -	Has not bee	Side room	Bay - she kn	Side room -	Either	Side room -	Bay - more	Bay	Side room -	Side room	Side room -	Bay (More s	Side (Privac	Side (privac	Side room (t
				Single/mixed sex?	Mixed	Mixed	Mixed	Either	Either	Either	Either	Mixed	Single sex	Mixed	Mixed	Either	Mixed	Single	Single	Single - for t	Single	Single - privac
				Side room - isolated?	N/A	N	Y - felt bore	N/A	Y - when st	Y - felt isolat	Y - could no	N	Y - felt cut o	N	Y - isolated	N	N	N/A	Y - did not fe	Y - N as fami	N/A	N/A
				Enough structural privacy barriers?	Y	Y	Y	Y	Y	Y	Y	N - curtains	Y	Y	Y	Y	N - had to g	Y	Y	Y	Y	Y (plus wind
				Washing/bathroom facilities	Doesn't like	Y	Y	N - separat	N - separat	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y - I have cr	Y	Shower cur	Y
				Most Comfortable for alone time?	Bed	Bed	Side room -	Bed	Bed	Bed	Bed	Bed	The quiet ro	Bed	Bed or quiet	Bed	Side room	Bed or Side	Bed	lounge, pare	Side room, p	Bed/comput
				Have enough privacy on the ward?	Y	Y	Y	Sometimes	Y - less on	Y	Y	Y	Sometimes	Y	Y - as good	Y	Y	Y	Sort of, ther	Y, but wouk	Not at busy	Y
				Staff members to they talk to?	Cat, nurses	All	All	Nurses	All	She trusts 3	All	All	Nurses or y	Nurses	All	All	All	Most nurses	nurses	nurses, som	nurses, nigh	nurses
				Staff understand need for privacy?	Y	Y	Y - staff wo	Y	Y	Y	Y	Y	Nurses unde	Y	Y	Y	Y	Y	Y - but not a	Y	Y	Y, allowed t
				Ward suitable for your age?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y - friendly a	Y
				At ease on the ward? 1-5		4		5	3 - but gettin		4		5		5		5		5	3 - as medica		4
				Which activities do you take part in?	Arts & craft	Arts & craft	Arts & craft	Arts & craft	Arts & craft	Arts & craft	Pizza night,	Arts & craft	Arts & craft	Arts & craft	Arts & craft	Arts & craft	Arts & craft	Arts & craft	Movie night,	Pizza night,	pizza night,	pizza night,
				Enjoy activities provided?	Y	Y	Y	N	Y	Y	Liked guitar	Y	Y	Y	Y	Y	Y	Y	Y	I have a go	Y	Y-try them a
				Friends/siblings join in?	Y	Y	Y	N	N	Siblings don	N	Sometimes	Y	Y	Y	Y	Y	Y	Y	Y	Y - massage	N
				Have many visitors?	Y - every ni	Y	Y - has bes	Some	Some	N	Some	N	Y	Y	Y	N	Y	Y	Y	Y mainly far	a couple, so	Y - everyday
				Invite siblings/friends from outside ward?	Y	Y	Y	Y	N - has Asp	N - too far fo	Y	N - live quite	Y	Y	Y	Y	Sometimes	Y	Y	Only girlfriend	Y	Y
				Like having friends come to visit?	Y	Y	Y	Y	N - has Asp	N - feels cor	Y	Y	Y - she miss	Y	Y	Y	Y	Y	Y	Y	Y	Y - I like to sh
				Feel about having friends over?	Happy		Stops her fr	Sometimes	Prefer to h	She wouln	Likes when	Likes it whe	Really good	Fun, enjoys	Likes having	Likes when	Is ok about	Likes it, kee	Comfortable	N - what m	Comfortable	At ease
				Friends/siblings stay overnight?	N	N	N	N	N	N	N	N	N	Y - it was n	N - under 16	Y	N	N	Didn't know	N - the mach	Y	N
				Friends/siblings use long visiting hrs?	Y	Y	Y	Y	N	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
				What do you think of long visiting hrs?	Very good	Good	Likes it	Good	Helpful bu	Good	Good	Good	Very importa	Good, can s	Excellent	Great	Happy for p	It is good, m	Better than c	Flexible, let	Not restrict	Flexibility
				Use phone/computer?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	No signal fo	Y	Y	Y	Y	Y	Y	Y
				Social networks?	Y - Faceboo	Y - Faceboo	Y - Faceboo	Y - Faceboo	Y - Faceboo	Y - Faceboo	Y - Faceboo	Y - Faceboo	N	Y - Faceboo	Y - Faceboo	Y - faceboo	Y - faceboo	Y - Faceboo	Y - Faceboo	Y - Faceboo	Y - faceboo	Y - faceboo
				Made new friends on ward?	Y	Y	Y	N	Talks to so	Y	Some, but di	Y	Y	Y	Y	Y	N	Y	N - not been	Y - lots as p	Y	Y

Questions asked were listed in the rows, grouped together by their themes

Separate sheets were created to allow formation of tables of data, taken from the original data, to create graphs

Appendix 3: Measure of Inter-rater Variation

	Value of Cohen's Kappa (unweighted)	Standard Error	95 % Confidence Intervals		Strength of agreement
			Lower	Upper	
Question 1	<i>0.78</i>	0.08	0.63	0.94	<i>Good</i>
Question 2	<i>0.85</i>	0.07	0.72	0.98	<i>Very Good</i>
Question 3	<i>0.81</i>	0.09	0.64	1.00	<i>Very Good</i>
Question 4	<i>0.70</i>	0.09	0.52	0.87	<i>Good</i>
Question 5	<i>0.80</i>	0.82	0.63	0.95	<i>Very Good</i>

Table 3 – Inter-rater Variation

Table displaying the Cohen's Kappa values of each open question that was selected to measuring inter-rater variation. The strength of agreement classification of Kappa is written as determined by Fleiss et al (1969)²⁶.