AUDIT OF TYA CANCER PATIENT’S VIEWS ON SUPPORTIVE SERVICES OFFERED BY UCLH

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Patient Representatives of the TYACNCG
METHODS

- Questionnaires asking questions regarding different aspects of support provided at UCLH were given to:
  - Patients aged 13-24 years who were currently receiving treatment or had previously receiving treatment for cancer at UCLH
  - Families of patients in the above categories
- The questionnaire was developed in partnership between the senior TYA service team at UCLH, the Teenage Cancer Trust and CLIC charities.
  - Demographics
  - Access to support
  - Groups
  - Support network days
  - End of treatment
- Questionnaires were given out to all TYA patients attending in-patient, out-patient, daycare or ambulatory care facilities during a one month period (July 2012).
- TYA CNSs also sent out e-mails to all TYA patients with a link to complete the same questionnaire via an on-line survey at https://docs.google.com/spreadsheet/viewform?formkey=dDNBSGFpbTVaRFd2UENQeDJsSngyWUE6MQ#gid=0 (sent out at the beginning of July).
DEMOGRAPHICS

- A total of 55 questionnaires were received (20 via the online survey and 35 paper copies).
- 45 respondents were patients, 9 were parents or carers and 1 did not state whether they were a patient or parent/carer.
- 27 respondents were male, 23 were female and 5 did not give their gender.
- The median age of responders was 19 years old, with a range of 14-24 years.
- 27 patients were aged between 13-19 years and treated in the CYPCS, 18 patients were aged 20-24 years and were treated in adult cancer services.
### DEMOGRAPHICS

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>N (patient respondent/parent or carer)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ewing's Sarcoma</td>
<td>9 (7/2)</td>
</tr>
<tr>
<td>Acute Leukaemia</td>
<td>8 (8/0)</td>
</tr>
<tr>
<td>Osteosarcoma</td>
<td>7 (5/2)</td>
</tr>
<tr>
<td>Hodgkin Lymphoma</td>
<td>6 (4/2)</td>
</tr>
<tr>
<td>Non specified sarcoma</td>
<td>6 (5/1)</td>
</tr>
<tr>
<td>NHL</td>
<td>5 (5/0)</td>
</tr>
<tr>
<td>Colon/rectum</td>
<td>2 (2/0)</td>
</tr>
<tr>
<td>Germ cell</td>
<td>2 (2/0)</td>
</tr>
<tr>
<td>Breast</td>
<td>1 (1/0)</td>
</tr>
<tr>
<td>BMT</td>
<td>1 (1/0)</td>
</tr>
<tr>
<td>Aplastic anaemia</td>
<td>1 (1/0)</td>
</tr>
<tr>
<td>Penile</td>
<td>1 (0/1)</td>
</tr>
<tr>
<td>Not stated</td>
<td>6 (4/1, unknown for 1)</td>
</tr>
</tbody>
</table>

- All patient groups represented except for neuro-onc
- 22 sarcoma
- 22 haematology and transplant
- 6 non-sarcoma oncology
- Year of diagnosis 2005 onwards
- 64% diagnosed from 2010 onwards
SUPPORT GIVEN

• All patients (42/45) and all parents or carers (9/9) who responded felt that they could access support when they wanted it.

• 2 parents/carers also responded ‘no’ to this question – one annotated that they felt supported at the PTC but not when they were at their local hospital.
MOST IMPORTANT THINGS- PATIENTS

- Access to written and other information when needed and at an appropriate rate (‘step by step’) – having an understanding of the disease and treatment – information needs ongoing throughout treatment
- Attitude of all staff and team working
- Having contact numbers and knowing who to speak to
- Key members of team providing support
  - Ward nurses
  - CNS
  - CLIC social worker
  - Activity coordinators
- Access to 24/7 room and activities
- Access to school and teachers
- Pleasant environment
MOST IMPORTANT THINGS
- PARENTS/CARERS

- Identified CNS
- Access to CLIC social workers
- Access to information in non-medical terms
- Staying with patient and access to Paul’s House
- Contact numbers

Knowledge & Skill of a very dedicated team of professionals

You don’t feel as though you’re wasting their time, you’re made to feel so relaxed and welcome and part of a family they understand that because of the shock that you won’t be able to take a lot in, they are very patient and understanding

having the specialty nurse on hand and been given her mobile phone number so you may call anytime
AREAS FOR IMPROVEMENT

- Travelling for tests which could have been performed locally
- More social work input
- Difficult to contact ward
- More practical and emotional support for family members
- Practical advice at end of treatment
- Better contact information for the local hospital.

I still talk of UCLH now in the highest regard to anybody who will listen! In my opinion a true centre of excellence with staff to match (Parent).

After cancer is finished, fitness and dietary help. I was a professional golfer and felt I didn't get help to get back into my sport/job (patient).
91% teenagers and 62% young adults offered additional support
THINGS THAT WERE HELPFUL

PATIENTS
Financial advice/offsetting costs/parking permit
Access to treats eg Starlight, special days out, make a wish, TCT
Complimentary therapy team
School
Dietary advice

PARENTS/CARERS
Psychotherapy
Complimentary therapy
Use of Paul’s House
Additional support for family

I was offered extra support but didn’t think I needed it.
Only 9 patients and 1 parent/carer had attended a support group

Everyone getting together to play games, have a laugh, eat some pizzas, and meeting new people and learning new games.

I attended a make up session which was really fun. I also got to meet a girl that I went to Centre Parks with which was one amazing experience.

I was either too unwell to attend when I was in hospital or if I was at home it was too far to travel there and back as I tire easily.

Happy with my own time. Nice to have the offer of group time but prefer time on my own.
63% of patients and 67% parents/carers thought it would be valuable to meet with other young people and their families.

Only 4 patients and 1 parent/carer had attended.

Have you heard of the support network?
GOOD

Talking to others going through the same thing – not alone
May learn how to cope from others experiences – chemotherapy, emotionally
Sharing experiences – helping each other

BAD

Prefer time with friends and family
Do not want to focus on illness/not be part of that club/put it behind me
Do not wish to discuss with others
Not confident

Few people in the outside world know what it’s really like to go through something like that, unless they’ve had a life threatening illness. It’s helpful to talk to people that understand what you’ve been through, won’t feel sorry for you and let it define you, but accept it and have a conversation about it without being ‘weird’.

My family have found talking to others useful whereas I really haven’t. I would rather spend my time not focusing on the illness but can see how it would be useful. I found reading about others success stories and reading how well known people had overcome cancer helpful but face to face not so much. When I was well I just wanted to be away from all reminders. Sometimes it felt a bit like a club that I didn’t want to belong to
I would like to see the patients smiling and having fun... just something to make them happy.

**INTEREST IN SOCIAL DAYS**

- Having fun
- Talking
- Picnic
- Beach
- Film
- Bowling
- BBQ
- Games, football
- Makeover
- Extreme activity days

I would like to see the patients smiling and having fun... just something to make them happy.
34/44 patients and 8/9 parents/carers thought sibling days were important
OTHER IDEAS FOR SUPPORT

Meet other young people who had survived when going through treatment – ward visits

Extend the young persons ward to 25 and ask patients whether they wish to be treated on a young persons ward or adult ward

Provide a space where teenagers and young adult inpatients could meet if cared for in different wards

Provide overnight accommodation for parents of young adults receiving in patient care

Help and career advice for sportsmen and women undergoing cancer treatment
END OF TREATMENT

Do you feel you understand what ‘End of Treatment’ means to you and your family?

All of those responding no said they would like to have more information about the end of treatment.

Staff identified as helpful

Consultant/doctors
Nurses – CNS, daycare nurses
CLIC social worker
No-one/no plan
END OF TREATMENT

Things that patients would have liked to know at the end of treatment

An end of treatment plan – what happens next, how often are check-ups, what are the potential late effects, information booklet
Contact numbers if concerns
Information
    support groups, family days out
    how to recover well
    how to ‘move on’ from treatment
    how to gain confidence and strength again to lead a good life
    does cancer and treatment have to go on my CV
    when can I eat and drink the things I used to
Help to get back into physical shape and lead a healthy life
Help in getting back to work
Social worker contact when no longer ‘on books’
Counselling
Inform
Completion pack – goodie bag
Talking to someone who has completed treatment
END OF TREATMENT CLINIC?
END OF TREATMENT

Help in re-building confidence
Help and advice regarding;
  exercise during and after chemo (important for confidence also)
  returning to school or work/career advice
  travel insurance
  how to explain cancer and treatment to family and friends
  nutition
  relaxation and fatigue management

Contact details of how to access help
Support
for family
  closer to home
how to carry on as a parent
post treatment emotional and practical issues
Provide young adult in-patient facility

I suffered panic attacks after that with the fear of getting ill again and more support was needed.
SUMMARY

Good representative survey

The TYA services offers excellent overall support to its patients and families.

Key health professionals identified as providing support were the ward nurses, clinical nurse specialists, CLIC Sargeant social workers and activity coordinators.

91% teenagers and 62% young adults were offered specialist support, and all but 3 found this helpful.

Few patients, parents or carers attended support groups. This was often due to a lack of awareness of the groups.

Very few patients, parents or carers had attended the support network (around 50% had not heard of the support network) although 64% felt that it would be useful to meet up with other young people and their families.
Around 50% were interested in attending social days. Young people were keen that these days should focus on activities and having fun.

79% felt that support days should be available for brothers or sisters.

42% were interested in attending an end of treatment clinic. There is a strong need for support and information regarding to returning to a normal life, re-building confidence, living a healthy life, late effects and ongoing plan and who to contact with concerns after treatment has finished.

There is a need to provide a young adult in-patient facility with equity of access to support for this age group.
RECOMMENDATIONS

Ensure and develop support structure for those health professionals delivering most support eg ward nurses, clinical nurse specialists, CLIC social work team and activity coordinators

Develop support group programme for patients, parents and carers and a mechanisms for letting them know what is available eg posters, leaflets

Feedback information gained in this audit to the support network team

Ensure all patients have an end of treatment summary, which is given to the patient.

Develop an end of treatment clinic for those who would like to attend. Develop end of treatment programme with sessions on getting back to normal, fatigue management, nutrition and exercise.

Establish young adult in-patient facility. Review how psychosocial support is provided for young adult patients