

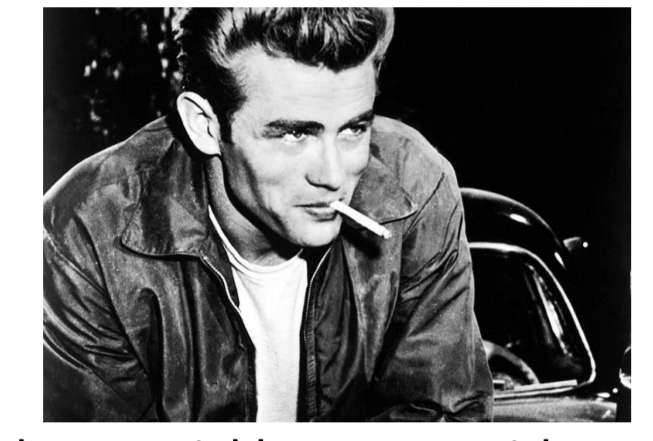


Health Promotion Advice for Childhood Cancer Survivors: When, Who, Where and How?

Jonny Mayes, Newcastle University, 3rd Year Medical Student
j.w.mayes@ncl.ac.uk

Introduction

Teenagers are invincible - or so they think. Adolescence is a time characterized by risk-taking behavior and experimentation epitomized by one James Dean:



Normally this phase quickly passes without damaging consequences. However, for childhood cancer survivors the potential risks to their health are much greater, due to side-effects of treatment and recurrence of disease.

Approximately one in 700 young adults is a survivor of childhood/adolescent malignancy and 60% of long-term survivors have one or more chronic medical problem. Few studies have sought the views of survivors regarding lifestyle advice and preventing medical problems. Hence this study aimed to evaluate patients beliefs investigating the best possible way to provide helpful and engaging lifestyle advice for teenagers and young adults.

Methods

30 semi-structured interviews were conducted with survivors of paediatric cancer attending a long-term follow up clinic at the Great North Children's Hospital. To be eligible for the interviews survivors must be;

- Off treatment for >4 years.
- Aged 14 or older
- Absence of severe learning disabilities and/or memory loss.

All eligible patients were approached to avoid volunteer bias, with all 30 agreeing to participate in the study. The interviews were assessed to be a service evaluation so verbal consent was gained before interviews began. Data was analysed using basic content analysis. The occurrence of concepts and items throughout interview responses was calculated.



Me working hard on the project!

What I've Learnt from this Project...

- Interviewing patients has made me more confident in a clinical setting.
- The ability to engage and interest somebody you have just met is an important asset as a doctor and one I feel I have just begun with this project.
- How to plan, organise and complete a (successful) research project.

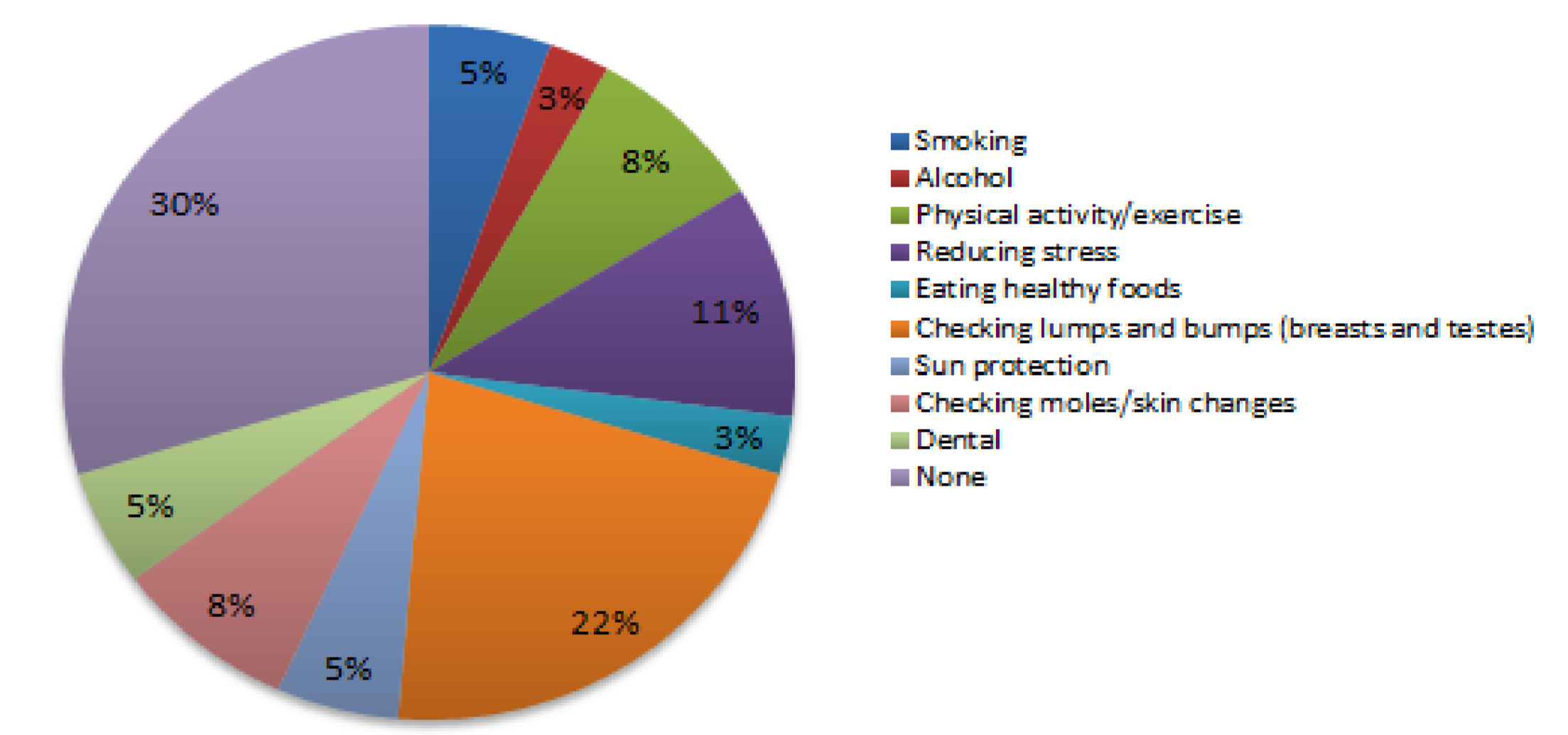
Results

1. Understanding health risks and the purpose of Long Term Follow Up (LTFU)

- ✓ Most patients believe they are aware of the possible long-term side effects relating to their cancer treatment, and this was explained to them by their consultant.
- ✓ Majority of patients feel they know enough about future health risks and have received the correct amount of information.
- ✓ Almost all patients were satisfied with their long term follow-up. They feel they received the support they needed, and have had ample opportunity to any questions they have.
- ✗ Almost all patients believe LTFU is about checking for the return of the original disease. For most patients ≥5 years off treatment, the true purpose of LTFU is to check for any late adverse effects of treatment and an opportunity to discuss any problems.

2. 'What lifestyle topics would you like to receive advice about?'

- This pie chart shows which topics patients wish to receive information about - some patients chose multiple topics, others chose none.
- 7 patients felt physical activity was the most important lifestyle topic, with 6 saying healthy eating and 4 stating checking for lumps and bumps.
- Checking lumps and bumps also came out on top as the topic patients felt they knew least about.
- The vast majority of patients were not interested in a separate appointment for lifestyle advice, although they found it reassuring to know it was there if needed.



3. Ideas about health promotion and lifestyle advice

- Most patients believe much of the information given is 'general knowledge' and 'common sense' but accept that it is still important and would like it to be discussed.
- 28/30 patients believe their consultant would be the best person to talk to about lifestyle advice.
- There was a range of answers concerning at what point this lifestyle advice should be given; patients who were younger at the time of disease felt it better to receive information post-treatment. Patients who were older at diagnosis preferred to be given lifestyle advice before and during treatment. The age when patients felt they were old enough to discuss lifestyle advice was 10-12.

Each 😊 = 2 Patients	YES	NO
Is Lifestyle Advice More Important for you as a Cancer Survivor?	😊😊😊😊😊😊😊😊😊😊	😞😞😞😞😞😞😞😞
Should Lifestyle advice be discussed with everyone coming to clinic?	😊😊😊😊😊😊😊😊😊😊😊😊	😞😞😞😞😞😞😞

4. Location and alternative methods of LTFU

- ❖ Location, location, location – patients over 18 were asked if they were concerned with attending the paediatric unit for their care. The majority were not, although some patients did express concerns they were 'taking valuable time away from younger children.'
- ❖ Many patients expressed interest in accessing lifestyle advice via interactive help such as apps - some of the positives stated by patients for this approach were 'avoids any embarrassing questions', 'easily accessible' and 'an interactive experience is much more interesting.' Despite this, patients still appreciated face-to-face conversation with their consultant.
- ❖ Patients usually did not like the idea of changing doctors from paediatric to adult oncologists as they felt they would lose the relationship they currently had, although a joint clinic or a detailed letter explaining the patient's experience usually were accepted as possible ways of transferring to more age-appropriate care.
- ❖ Numerous cancer survivors felt they would not want their GP to be responsible for their LTFU, often due to initial misdiagnosis or delayed diagnosis.

Key Clinical Points;

1. Clarification is needed for many patients about the purpose of LTFU and why they are returning to hospital.
2. Lifestyle advice should be discussed in LTFU clinics with an appropriate level of content for the patient's age, current lifestyle and treatment received.
3. Many survivors don't realise the importance their treatment has on their lifestyle, emphasising the importance of positive information about how lifestyle measures protect their future.

Acknowledgments

Special thanks must go to Rod Skinner, Nicola Davies and Morven Brown for their patience, time, expertise and support with this project. I would also like to thank all the patients and staff at the Great North Children's Hospital for participating in the study. Finally a big thank you to the Newcastle University Research Scholarship Fund