Teenage Cancer Trust Education & Advocacy Program: ‘Let’s talk about it’ A United Kingdom Approach

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Abstract. Cancer in the United Kingdom is viewed as a taboo subject, particularly with young people, who can enter adulthood with little knowledge about cancer and are often misinformed about the facts. Evidence suggests this lack of information can lead to significant delays in cancer diagnosis. Within the education system in the United Kingdom, there is no provision for cancer education, but as cancer is likely to affect more people each year, the Teenage Cancer Trust education program ‘Let’s talk about it’ aims to improve knowledge and awareness of cancer in secondary schools and offers advice on healthy living to all young people.

Keywords. Cancer, teenager, education

Introduction

Cancer accounts for 11% deaths in teenagers and young adults in the United Kingdom (UK) [1] and is ranked as the biggest cause of non-accidental death in this age group [2]. Evidence suggests that within this group there is a high risk of a delay in diagnosis, often because young people fail to recognize serious symptoms and avoid seeking help. Late diagnosis is considered a major factor contributing to poor cancer survival rates [3]. In a survey conducted in 2011 by Teenage Cancer Trust asking 300 young people with cancer about their diagnosis, 37% of them said that they ignored the symptoms initially, and 20% of them said that they waited several months before going to visit their general practitioner (GP). It is vital that young people be provided with the tools that will empower them to seek help and to take responsibility for their own health in a safe and structured environment. This is an aspect of education that schools in the UK fail to provide, meaning that young people are left without the knowledge and skills which should help them to swiftly recognize any issues with their health and bodies and push for a diagnosis.

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Teenage Cancer Trust has been campaigning for better treatment for teenagers and young adults with cancer for over 20 years. Formally established in 1994, the charity has been at the forefront of the battle to give them the best fighting chance and to make their experience as positive as possible. Fundamental to the work of the Teenage Cancer Trust is to provide education to young people about cancer so that there is a reduction in the number of young people receiving a delayed diagnosis.

Objectives

The main objectives of Teenage Cancer Trust education program ‘Let’s talk about it’ are to:

- Provide young people with information, education, and advice about cancer. The aim is to remove the stigma from cancer and demystify the disease by creating discussion within classroom settings on the signs and symptoms of cancer, its treatment, and emotional support issues surrounding the disease.
- Empower young people to manage their own health issues, to make informed choices about their health and well-being, and to evaluate personal choices and make changes if necessary.
- Promote healthy living to young people, with the aim of reducing the risk of developing cancer as an adult.

Implementation

The Education & Advocacy team has varied backgrounds including nursing, teaching, social work, and youth work. The program is offered to all secondary schools and further education colleges in the UK, which is approximately 6000. There are a number of ways the education program is delivered.

1. Classroom-based Presentations
Regionally based team members contact schools with an introduction to the topics covered within the education program. Any school interested in the program will receive a school education pack that contains information about teenage cancer and the education program. While the education program provided by Teenage Cancer Trust is aimed at raising awareness of young adult cancer, many young people in a school setting might also have a family experience of cancer and these presentations can help them to understand what support is available for the family of a cancer patient.

The numbers of students to whom the presentations are delivered vary depending on how the individual school has its working day structured. Usually class-sized groups are around 30, but it is common for the presentation to be delivered to an entire year group, which would be around 150 students. Within the presentations many topics are covered.

1.1. Topics Covered

What is cancer?
Why it is important to be aware of cancer and the impact it can have on a young person as well as families and siblings
Common teenage and young adult cancers
Issues relating to diagnosis—why young people often have a delay in diagnosis
How to spot the signs of cancer
Treatment
The impact of cancer on the body, the mind, relationships, fertility
What is important to young people with cancer?
Taking responsibility for one’s own health and well-being
The human papillomavirus (HPV) and cervical cancer

The sessions are delivered in a professional, positive, upbeat way and have been well received by all schools that have participated in an awareness session. Cancer-specific presentations, such as testicular and skin cancer, are also delivered.

2. Lesson Plans

In addition to the awareness presentation, the Teenage Cancer Trust education & advocacy team has also created lesson plans, which teachers can use independently. The current ones are based on skin cancer and sun awareness. These lesson plans identify the learning objectives from each session and also indicate the criteria they meet in terms of the national curriculum.
3. Learning Resource

The Teenage Cancer Trust education & advocacy team has developed a fully interactive learning resource, based on a teenage magazine, which seeks to engage students in a dialogue regarding the issues surrounding teenage cancer. The resource has been created to fit within the UK national curriculum. It offers students and teachers a fully supported, unique, and invaluable learning context complete with full teaching notes and lesson plans.

Observations

The work of the Teenage Cancer Trust education program has so far not been formally evaluated but it receives regular positive feedback from teachers and students.

“After your session one of the students went home and noticed a mole on her mum’s leg which she didn’t like the look of. The mum went to the doctors and has been referred to the hospital. Hopefully it will be nothing sinister but thanks again as your information has made a difference.”

“The talk was superb and in fact resulted in one of our students getting help for a testicular growth that he had been too afraid to tell anyone about prior to the talk and we are really keen to give other students the opportunity to learn about this important aspect of their health from an expert.”

The learning resource has also received positive feedback:

“There’s a real focus on developing emotional maturity and skills/qualities that will help young people in all areas of life, as well as in supporting cancer patients.”

“There is factual information about cancer but it’s not information overload which might put young people off, and there are clear pointers as to where to go if you want more information.”

At the present time, the education & advocacy team is embarking on a research study, which aims to highlight the benefits and advantages of the Teenage Cancer Trust education program and that it does have a lasting impact on young people and achieves the desired aims.

Results

Since the beginning of 2002 the following information has been gathered.
• The education & advocacy team members have spoken in 1500 education establishments
• 950,000 students have received an education session on teenage cancer.
• This summer 3000 education packs specifically created for our sun awareness campaign—‘shunburn’—have been sent to schools throughout the UK

The feedback from teachers since August 2009 is that:
• 98% of teachers thought that the quality and delivery were excellent
• 97.5% thought that the presentation achieved its aims in education about cancer
• 99% would rebook a presentation by the education & advocacy team
• 98% believed that cancer education should be on the national curriculum

Teenage Cancer Trust also asked young people who had been diagnosed with cancer about cancer education in schools. Of the 300 young people involved in this questioning, 65% said that learning about cancer at school would have helped them with their own cancer diagnosis.

Conclusions

The Teenage Cancer Trust education & advocacy team aims to inform, educate, and empower young people throughout the UK. The feedback received from schools, teachers, and students remains positive. This service is offered free of charge to every education establishment throughout the UK and meets various curriculum requirements. Uptake of the service does vary considerably throughout the UK. Due to the rigid timetables in schools and the number of subjects needing to be covered, schools aren’t as responsive to the program despite the acknowledged benefits and necessity for cancer education. Formal evaluation of the work of the education & advocacy team aims to highlight the benefits of the program with the aim of an increase in the uptake of the service. A recent survey by Macmillan Cancer Support found that 74% of the 12- to 19-year-olds would not know what to say to a friend with cancer and that 50% would avoid talking to them about it. It found that 37% thought cancer could be caused by knocks and bumps, and 12% thought cancer could be catching. These findings emphasize why the education program coordinated by Teenage Cancer Trust is so vitally important.

References