Lifestyle Advice Provision to Teenage and Young Adult Cancer

Patients: The Perspective of Health Professionals in the UK

In preparation for: Supportive Care in Cancer

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Abstract

Purpose: Health professionals are an important source of information for teenage and young adult (TYA) cancer patients. However, little is known about health professionals' provision of lifestyle advice to young people with cancer who are in their care.

Methods: An online survey was distributed to health professionals within the UK who identified themselves as working with TYA cancer patients. Health professionals awareness of lifestyle guidance, provision of lifestyle advice to young people, and views on lifestyle information format and delivery were explored.

Results: Ninety-five health professionals (44% nurses; 28% allied health professionals; 17% physicians) completed the survey. The majority (72%) of respondents were aware of some lifestyle guidance for cancer patients. However, less than half of TYA health professionals (46%) were able to successfully recall the source of the guidelines and less than a third reported proving specific advice to the majority of their patients on weight management, smoking, alcohol consumption and sun safety. Many health professionals (38%) felt they were not the right person to provide advice and cited lack of resources as a key barrier to advice provision. The majority (95%) reported being interested in a resource containing relevant lifestyle information that could be given to young people with cancer.

Conclusions: TYA health professionals' awareness of lifestyle guidance and provision of advice regarding health behaviour is sub-optimal. Clear and comprehensive guidance written specifically for TYA health professionals could overcome the reported barriers and improve professionals' confidence in addressing and providing advice on lifestyle to young people with cancer.

Keywords

Teenage, Young Adult, Cancer Patient, Health Professional, Lifestyle, Advice

Introduction

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Healthy lifestyle choices, such as being physically active and eating a healthy diet, may substantially improve the health and quality of life of teenagers and young adults (TYA) living with and beyond a cancer diagnosis [1-3]. Whereas obesity, smoking, heavy alcohol consumption and negligent sun practices (high levels of sun exposure and poor sun protection) are likely to exacerbate TYA cancer survivors' risk of treatment-related toxicity, chronic disease, secondary cancer and cancer recurrence [4-6]. Given that lifestyle habits formed during adolescence and young adulthood often continue throughout the life-course, it is vital to provide young people who have had a cancer diagnosis are provided with the support necessary to make informed choices about their health behaviour. Health professionals who work with TYA cancer survivors and/or TYA aged childhood cancer survivors are well positioned to provide young people living with and beyond cancer with the right support and guidance to make healthy lifestyle choices [7, 8]. Specific lifestyle recommendations written for TYA cancer survivors are contained within the Childrens' Oncology Group (COG) and Scottish Intercollegiate Guidance Network long-term followup guidelines for survivors of childhood, adolescent and young adulthood cancers. Specifically, health professionals are advised to provide health behaviour counselling to young people within the context of late-effects management, especially when regarding the treatment of cardiac problems and metabolic syndrome. While there is currently no formal guidance for TYA cancer survivors receiving treatment, there is general consensus that health professionals caring for young people with cancer have a duty to advocate the importance of healthy lifestyle choices throughout the cancer care pathway [8]. Health behaviour change interventions delivered early within the care pathway have the potential to mitigate the onset of treatment-related comorbidities and prevent the development of unhealthy lifestyle habits, such as inactivity and poor dietary intake, often noted during cancer therapy [9]. Moreover, a recent cross sectional survey of TYA cancer survivors (n=216,

mean age= 20 years) found young people with cancer are receptive to receiving advice and support

on health behaviour from the point of diagnosis onwards [10]. Several organisations (American Cancer Society, CanTeen, Institute of Medicine Livestrong Foundation, National Cancer Institute, National Cancer Comprehensive Network, and Teenagers and Young Adults with Cancer (TYAC)) have produced information resources or position statements relating to lifestyle for the interest of health professionals working with TYA cancer survivors both on and off treatment. Overall, these guidelines and information resources do not differ substantially from those written for adult cancer survivors: all advocate, to varying degrees, the importance of TYA cancer survivors remaining physically active, eating well-balanced diets, limiting alcohol intake, not smoking and being safe in the sun. Existing evidence, although limited to a small number of studies, suggests that many TYA cancer survivors are inactive, have poor dietary quality and engage in risky health behaviours such as drinking, smoking and tanning [11-14]. Nevertheless, previous studies in adult cancer survivors have demonstrated that a health recommendation from a professional can lead to positive lifestyle behaviour change [15, 16]. However, many TYA cancer survivors report unmet needs in relation to diet and exercise information, and alcohol and drug counselling [17, 18]. For example data from the United Kingdom (U.K) indicate many young people (36-70%) had not received advice about their health behaviour since their diagnosis [18]. Discrepancies between the number of TYA cancer survivors reporting a desire to discuss current health behaviours (>50%) at a follow-up care appointment, and the number reporting actually discussing health behaviour (~43%) have also previously been found within the U.K [19]. Studies of health professionals working within adult oncology settings suggest that awareness of the importance of lifestyle is generally low and that professionals perceive numerous barriers to providing such advice to their patients [20]. Previous studies of health professionals working with adult cancer survivors have also shown lack of knowledge, lack of time, and patient sensitivity to be perceived barriers to providing lifestyle advice [21-23].

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To our knowledge, little is known about TYA health professionals' familiarity with lifestyle guidance, and their current practices regarding the delivery of lifestyle advice to young people within their care. In addition, there is currently no data on TYA cancer specialists' views of how and when the best time in the cancer care pathway to deliver such advice would be [24]. Therefore, this study aimed to address these gaps in knowledge and explore health professionals working with TYA cancer patients' awareness of lifestyle guidance, level of lifestyle advice provision and views on the format and delivery of lifestyle advice to TYA cancer survivors. Health professionals perceived barriers to providing lifestyle advice were also explored.

Methods

Participants & Recruitment

Data were collected via an anonymous online survey. Health professionals (oncologists, haematologists, surgeons, cancer nurses and allied health professionals) working directly with TYA cancer patients in the UK were eligible to complete the survey. From May to November 2015, the web link to the survey was cascaded through the mailing lists of several UK based professional and charitable bodies specialising in the care of TYA cancer patients. The survey was also circulated by existing contacts within the NHS, London Cancer Network and the National Cancer Research Institute Teenage and Young Adult Clinical Studies Group (NRCI TYA CSG). Several reminders about the survey were posted upon the TYAC website and sent to services staff employed or affiliated with CLIC Sargent. TYAC is an organisation within the UK which aims to unite professionals working with young people with cancer and CLIC Sargent is a UK based cancer charity specialising in caring for and supporting young people, and their families, affected by cancer. This study was approved by University College London Ethics Committee (reference 4456/001). By following the online link and completing the survey participants consented to the use of their anonymous data.

Measures

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2 The development and design of the survey was based on previous work carried out by Williams and colleagues, who assessed knowledge and predictors of lifestyle advice in health professionals 3 4 working with adult breast, prostate and colorectal cancer patients [20]. The survey was adapted for 5 use among TYA specialists in consultation with a specialist clinical team led by RH. 6 Demographic questions included those relating to professional speciality and place of work. 7 Professional speciality questions included professional group, length of time in current role, length 8 of time working with young people, best fit description of patient age group, and patient cancer 9 group. Place of work questions investigated hospital affiliation (principal treatment 10 centre/designated hospital/other) and regional affiliation. 11 Awareness of lifestyle recommendations and guidelines was assessed using the question: 'Are you 12 familiar with any guidelines specifically for TYA cancer patients on any of the following lifestyle 13 topics?' Lifestyle topics included physical activity, diet, weight management, smoking, alcohol 14 consumption and sun safety. TYA health professionals' level of provision of lifestyle advice was 15 determined by two questions: 'With what percentage of your patients do you enquire about the 16 following lifestyle topics?' and 'To what percentage of your patients do you give advice about the 17 following lifestyle topics?' Response options for each questions was 'none', '1-25%', '26-50%', '51-18 75%','>75%'. Health professionals were asked to report barriers or problems they feel would prevent 19 them from providing advice to young people within their care. Response options were based upon 20 barriers previously reported within adult cancer survivorship literature. [21-23] TYA health professionals' opinions about the format and delivery of lifestyle information to young 21 22 people with cancer were also explored. Delivery of lifestyle advice was assessed by the question; 'If 23 you were to give advice on the following lifestyle topics, what form does this advice usually take? 24 Response options included 'giving verbal advice', 'giving written advice e.g. leaflet/ pamphlet',

'referring to a website', 'referring to another health professional' or 'other'. Health professionals

1 were asked to report how best they thought TYA cancer survivors would like to receive information

about lifestyle (response options included 'leaflet or pamphlet', 'website', 'mobile app', 'other') and

3 when in the cancer care pathway ('before treatment', 'during treatment', '0-6 months' 'post-

treatment', '6-12 months post treatment', or '12+ months post treatment') lifestyle information

should first be introduced to young people with cancer.

Analyses

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7 All survey responses were downloaded and transferred to statistical package SPSS Version 22.

Descriptive statistics were produced to describe the demographics of respondents and the

proportion of health professionals overall and within each professional group who were familiar

with lifestyle guidance, and reported enquiring about health behaviour and providing advice to the

majority (>75%) of their patients. Descriptive statistics were also produced to report health

professionals perceived barriers to providing lifestyle advice and views on the format and delivery of

such advice. Exact significance tests for pearsons chi-square analyses were performed to examine

potential differences between professional groups regarding familiarity with lifestyle guidance,

enquiry about lifestyle and lifestyle advice provision.

Open-response answers were transferred into qualitative data analysis software (NVivo, Version 11)

and coded line-by-line. The process of content analysis as outlined by ELo and Kyngas (2008) was

followed. A deductive approach to analysis was taken wherein open responses to each question

were grouped together and the content was analysed for patterns or themes. The final coding was

analysed and emerging themes were categorised and enumerated. In total, 79 individual open

response comments were analysed.

Results

Response Rate

1 The exact reach of the survey is unknown as the link to the survey was posted online or cascaded

independently via various professional organisations and individuals. 132 health professionals

followed the survey link and consented to participating and 114 (86%) of these completed at least

one question. Of these 114, 95 (83%) completed all of the questions relevant to the current study.

There were no significant differences in background demographics between full and partial

responders.

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Sample Characteristics

Sample characteristics are shown in **Table 1 and 2**. 44% (n=42) of respondents were nurses. 73%

(n=69) identified themselves as working with young people aged 13-24 years of age and 63% (n=60)

had been working with young people with cancer for more than 5 years. Most respondents (69%,

n=66) worked with patients across all cancer sites and were based within a principal treatment

centre (68%, n=65). The survey had a response from at least one health professional from each of

the home nations (England, Scotland, Wales, and Northern Ireland) within the UK, however a large

proportion of respondents worked in London (33%, n=31) and the South of England (26%, n=25).

Awareness of lifestyle guidance

Table 3 shows the proportion of health professionals who reported being aware of lifestyle guidelines for each health behaviour. More health professionals were aware of guidance relating to physical activity and diet (62% and 60% respectively) than weight management, smoking, or alcohol consumption (40-59%). 72% (n=68) of health professionals were aware of guidance on one or more health behaviour. Of these, 54% (n=37) could not recall the specific details of the guidance, and most cited charitable bodies such as the Teenage Cancer Trust, Childrens' Cancer and Leukaemia Group

(CCLG) and Macmillan Cancer Support as the source. 24% (n=23) of respondents reported being

- 1 unaware of any lifestyle guidance for TYA cancer patients. There were no significant differences in
- 2 the awareness of lifestyle guidance between professional groups.

Levels of enquiry about and provision of lifestyle advice

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advice.

4 Table 3 shows the proportion of respondents who reported enquiring about lifestyle and providing

lifestyle advice to the majority (>75%) of patients within their care. Overall, approximately half (45-

55%) of professionals surveyed reported enquiring about physical activity, diet, smoking and drinking

alcohol with more than three-quarters of their patients. A larger proportion of health professionals

asked about and provided advice on diet and physical activity than any of the other health

behaviours. Many health professionals surveyed reported that they provide advice on smoking (54%,

n=51) or alcohol consumption (48%, n=46) to less than a quarter of their patients. Similarly 43%

(n=41) and 44% (n=42) of health professionals reported starting conversation with very few (0-25%)

of their patients about weight management and sun safety.

As shown in **Table 3**, group differences were not observed between physicians and nurses for enquiry or advice provision on any health behaviour. There were no significant differences in the proportion of groups of health professionals who reported enquiring about weight management, or enquiring and providing advice on physical activity. Group differences for enquiry and provision of advice on diet, smoking, alcohol consumption and sun safety were observed between professionals who were physicians/nurses and those who were allied health professionals, or reported their profession as 'other'. There were no significant difference between professional groups who identified themselves working with TYA cancer survivors aged 13-24, versus those who reported working with young people in the older age range (18-39 years) for level of enquiry or provision of

Reported patient interest in advice

- 1 Most (68%-87%) of respondents reported that very few (<25%) of their patients asked them directly
- 2 for information about weight management, smoking, alcohol consumption or sun safety. Only 27%
- 3 (n=28) of respondents reported that more than half of their patients ask for information about
- 4 physical activity: and only 35% (n=36) reported that more than half of their patients asked for
- 5 information about diet. The percentage of respondents who reported that no young people in their
- 6 care asked for specific advice about smoking, drinking and sun safety was 42% (n=43), 40% (n=41),
- 7 and 36% (n=36), respectively.

Delivery of lifestyle advice

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As shown in **Figure 1**, health professionals most commonly opted to provide advice either verbally or by referring their patients to another health professional. Although very few respondents reported actually signposting patients in the direction of information online, open responses suggested electronic resources (such as websites or mobile apps) were considered to be acceptable formats of lifestyle information delivery. In the open response sections of the survey, health professionals reported that the format of information delivery was dependent upon on the needs of the patient and that information should be available in a range of formats to reflect differences in patient preferences. 43% (n=41) of health professionals surveyed believed young people with cancer should first be offered lifestyle advice during treatment, 33% (n=31) believed lifestyle advice should be first offered before treatment and 22% (n=21) believed lifestyle advice should be first offered up to 6 months post treatment. Encouragingly, 95% (n=91) said they would be interested in a resource containing relevant lifestyle information which they could give to their patients, and 76% (n=72) perceived no problems in providing such information to young people with cancer.

Barriers to providing lifestyle advice

- 23 The most common barrier was 'not being the right person to give advice' 38% (n=36); followed by
- 24 perception of 'patient feeling too frail or unwell' 36% (n=34), and perceived lack of patient interest

29% (n=28). 20% (n=19) of the health professionals surveyed felt that 'lack of clear guidance' was a barrier to providing lifestyle advice and 17% (n=16) felt that 'lack of time' was a barrier. No respondents cited 'seeming to blame the patient' as a barrier to providing lifestyle advice and only 12% (n=11) cited the feeling of 'being judgemental of their choices' as a barrier. Within open responses (Table 4) the lack of specific information and guidance about lifestyle for TYA cancer health professionals and the need to be sensitive towards patients' needs and sustain good relationships with patients was emphasised. Lack of knowledge or professional support was also highlighted alongside perceived low levels of patient interest in lifestyle information.

Discussion

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This is the first detailed study to investigate TYA cancer health professionals' knowledge of lifestyle guidance and provision of lifestyle advice to young people within their care. Awareness and familiarity of lifestyle guidance and enquiry about lifestyle behaviours was generally modest among health professionals working with TYA cancer patients, and few TYA health professionals provided lifestyle advice to the majority of patients within their care. The complexity of providing lifestyle advice to young people with cancer, and the need to provide education and tailored resources related to lifestyle was highlighted. Although the majority (72%) of survey respondents reported awareness of some lifestyle guidelines, over half (54%) of these professionals could not recall the source of this guidance, suggesting limited knowledge and familiarity with the guideline content. These findings are similar to studies of health professionals working with adult cancer patients [20]. Low to moderate levels of familiarity with lifestyle guidance among health professionals working with TYA cancer patients is perhaps unsurprising, as although some charitable bodies and medical groups have produced information and guidance about lifestyle topics, these resources often contain a wide array of information on a variety of topics, with only small sections dedicated to lifestyle behaviour and non-specific guidance (such as 'should remain active'). In addition, although guidance relating to lifestyle and cancer has been produced by bodies such as the World Cancer Research Fund and American Institute for Cancer Research, the focus of this guidance is aimed at adults and contains little specific reference to TYA cancer patients or their needs. The lack of specific lifestyle guidance is likely in part due to a lack of lifestyle intervention trials in the TYA age group and further research in this area is warranted [25, 26].

Less than half of the health professionals surveyed reported giving advice on physical activity or diet to the majority (>75%) of patients in their care. Even fewer (less than a third) reported providing specific advice about weight management, smoking, drinking or sun safety to the majority of their patients. These findings suggest that health professionals working with TYA cancer patients do not routinely initiate conversations about lifestyle behaviours or provide lifestyle advice to their patients. With regard to physical activity, the relatively low level of advice provision may relate to previously debated confusion regarding the safety of encouraging young people with cancer to be active [27, 28]. This notion could also apply to weight management and diet where 'best practice' recommendations for TYA cancer patients are yet to be devised due to lack of clear evidence. However, for behaviours such as smoking, drinking, and tanning which have well acknowledged negative associations with health [29], the finding that very few health professionals enquire about or provide advice on these topics was surprising. Nevertheless, previous studies have found similar patterns and rates of lifestyle advice provision in surveys of health professionals working with adult cancer patients. [20, 22, 30].

The low level of enquiry about lifestyle and provision of lifestyle advice from TYA health professionals may in part be explained by professionals' report that very few of their patients ask directly for information about individual lifestyle behaviours. The majority of health professionals surveyed (68% -86%) reported that less than half of young people within their care asked them directly for lifestyle information. The finding that very few young people with cancer ask directly for information about lifestyle was unexpected given previous reports of high levels of patient interest

in receiving advice on this subject [31, 32]. TYA health professionals may perceive low levels of patient enquiry about lifestyle as a lack of interest. However, a recent roundtable workshop addressing the needs and the lifestyle challenges of TYA cancer survivors concluded that health professionals working with TYA cancer patients can and should initiate discussions regarding lifestyle behaviour [8]. A large proportion of health professionals selected at least one barrier from the formulated list or cited their own barrier to initiating discussion about or providing advice on lifestyle behaviours. Barriers were most commonly centred on patient-related factors such as lack of interest, being sensitive to their emotional needs and maintaining good patient relationships. Consistent with previous studies of health professionals working in adult oncology [22] one of the most commonly endorsed barriers to providing lifestyle advice was perception of 'not being the right person to provide advice'. This could suggest TYA health professionals believe that addressing lifestyle behaviours and providing lifestyle advice is outside of their professional duty. The need for specifically tailored lifestyle guidance to be made available to all health professionals working with TYA cancer patients was highlighted within open responses. Clear and comprehensive guidance

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and maintaining patient relationships.

Findings from this study suggest that professionals were more likely to address (enquire to patients about) and provide advice on physical activity and diet than weight management, smoking, drinking alcohol, or sun safety. The discrepancies between health behaviours suggest that TYA health professionals may be reluctant to engage in conversation about sensitive issues (such as weight) and 'risky' health behaviours (such as smoking, drinking and unsafe sun practices) and may need additional support and guidance on how best to address these issues, or access evidence-based referral pathways.

written specifically for TYA health professionals could improve professionals' confidence in

addressing and providing advice on lifestyle behaviour whilst remaining sensitive to patient needs

Nevertheless, despite the numerous perceived barriers and problems to providing lifestyle advice, over 90% of health professionals surveyed were interested in a resource containing relevant lifestyle information they could give to their patients. Although the most commonly reported method of advice delivery was verbal, those surveyed acknowledged the need to provide young people with advice in a range of formats, and at a suitable time for the individual patient. The finding that TYA health professionals seldom refer young people within their care to websites may be explained by the current limited availability of lifestyle information specific to young people with cancer. With regard to the timing of delivery, the largest proportion of respondents believed lifestyle advice should first be provided to TYA cancer patients during treatment. This finding is consistent with emerging evidence that healthy lifestyle behaviours during treatment have a positive impact on quality of life and could influence cancer outcomes among young people [33, 34].

Although this is the first study to explore TYA health professionals' knowledge of lifestyle guidance, provision of lifestyle advice and barriers to providing lifestyle advice, a number of limitations must

provision of lifestyle advice and barriers to providing lifestyle advice, a number of limitations must be addressed. Firstly, we do not have data on the proportion of respondents who specifically work in long-term follow up or with specific out-patient groups. In particular, as demonstrated by the wide confidence intervals, the small sample size among some professional groups (specifically physicians) limited our ability to establish precise estimates of between group differences in lifestyle guidance familiarity, enquiry or provision of advice. Moreover, given the broad expertise and clinical roles carried out by allied health professionals it is likely the group differences which were found in the chi-square analyses are arbitrary. However, cancer is relatively uncommon in young people, and the number of health professionals who responded to the survey can be considered as quite large within the TYA health profession. Although the majority of respondents were nurses and were based within London or South East England, survey respondents typically worked with patients with a range of cancer diagnoses and had been working with young people with cancer for more than five years. Health professionals who have been working with TYA cancer patients for longer may have greater appreciation of the importance of promoting health lifestyle choices to young people with

cancer and therefore may have been more motivated to participate within the survey. This could suggest that, in general, TYA health professionals who did not complete the survey have poorer knowledge about lifestyle and are less likely to give lifestyle advice than those who completed the survey. The results of this study suggest lifestyle advice provision to young people with cancer may be a complex task. A 'one-size-fits-all' approach to lifestyle information delivery to TYA cancer patients is unlikely to be appropriate given the range of health needs and information comprehension abilities existing within this patient group. Future work should aim to further explore, within a larger sample, TYA health professionals' specific knowledge and understanding of lifestyle guidance and perceived importance of providing lifestyle advice to young people with cancer. The development of clear and succinct guidance on lifestyle for health professionals working with TYA cancer patients is vital as supporting young people with cancer to adopt healthy lifestyle choices which may prevent some of the short-term, and long-term, consequences of cancer treatment experienced by this unique age group [24]. Such information resources should also outline strategies to engage both TYA health professionals and TYA cancer patients in health behaviour promotion initiatives. Such resources have the potential to support professionals to successfully integrate health behaviour promotion into usual care routines. As previously highlighted, the inclusion of specific information about lifestyle and health behaviour within long-term follow-up guidelines for TYA cancer survivors would be a positive first step [35]. In conclusion, this study highlights the complexity of providing lifestyle advice to TYA cancer survivors. Although the majority of respondents thought lifestyle advice should first be provided to TYA cancer patients during treatment a range of barriers and problems to addressing lifestyle behaviour during conversation and providing advice on some specific behaviours were raised. TYA

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health professionals' high level of interest in receiving resources containing relevant lifestyle

information which could be given to patients was encouraging and supports the growing body of

- 1 evidence that health behaviour promotion among TYA cancer survivors is a critical topic to address
- 2 both in research and clinical practice. Efforts are required to ensure professionals working with TYA
- 3 cancer survivors have the confidence and skills to address lifestyle during consultations and provide
- 4 sound advice on individual health behaviours.
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