

Background

Approximately 2600 teenagers and young adults (TYA) are diagnosed with cancer in the UK each year¹. Although survival varies by cancer type, 80% of young people diagnosed with cancer will survive beyond 5 years.² However, the vast majority of TYA cancer survivors will suffer late effects of treatment, including debilitating fatigue, cardiovascular problems, and impaired metabolic or physical function.³ There is need to develop strategies to reduce treatment-related side effects and preserve health-related quality of life. Trial data from adult patients with solid tumors suggest that positive health promoting behaviors (particularly physical activity) can improve multiple outcomes after diagnosis and may reduce the impact of treatment-related toxicities.^{4,5,6} There is also evidence that health-risk behaviors (e.g. smoking, excessive alcohol consumption and sun exposure) may be particularly harmful for TYAs after a cancer diagnosis. Although more trials in TYAs are required, the strength of current evidence has prompted professional organizations, such as the Children's Oncology Group, to now provide lifestyle recommendations for TYAs. In the UK, the Independent Cancer Task Force currently recommends that all patients receive appropriate health behavior advice as a part of their care.

A growing body of evidence highlights the crucial role that healthcare professionals (HPs) play in health promotion amongst TYA cancer patients. Research from our group has found that the majority of TYA patients turn to HPs for guidance on general health behavior advice, citing them as trustworthy and reliable sources of information^{7,8}. TYA patient interest in receiving health behavior advice is also high with 71% of young people (sample, n=216) with cancer reporting interest in receiving health behavior advice; the most commonly desired topics of advice were physical activity (87%), weight (87%), and diet (83%)⁷. However, when surveyed only 46% of

HPs working with TYA (TYA-HPs) (n=95) in the United Kingdom were able to successfully recall health behavior guidelines and only half of professionals (45-55%) surveyed reported inquiring about physical activity (PA), diet, smoking and drinking alcohol with the majority of their patients⁹. Barriers included lack of perceived patient interest, professionals' lack of knowledge or skills about providing such advice, and professionals' lack of time. These findings highlight a clear need for an intervention for TYA-HPs to enhance their capability and skills in providing health behavior advice to their patients.

Existing studies of TYA-HPs have relied upon self-report to identify factors influencing health behavior promotion. While useful, these studies do not contextualize the experiences of TYA-HPs when providing advice or provide insight to potential intervention strategies which may facilitate advice delivery. To aid with intervention development, the Medical Research Council¹⁰ and the National Institute of Health and Care Excellence (NICE)¹¹ recommend a coherent theoretical framework be used, such as the COM-B model as described by Michie and colleagues¹². This model describes a TYA cancer specialist's 'Behavior' as dependant on three separate tenets: 'Capability' (the specialist's knowledge and skills used to deliver advice), 'Opportunity' (the physical and social factors that lie outside the specialist which make advice provision possible) and 'Motivation' (the specialist's intrinsic and extrinsic motivation to deliver the advice). The COM-B model has been previously used in qualitative research to explore healthcare professionals' behaviors in primary care, psychiatry and post-natal care settings^{13,14}. In the cancer setting, the COM-B model has been used in a pilot study investigating PA advice delivery by nurses, and successfully preceded the development of an intervention in a follow-up study^{15,16}.

Understanding factors influencing TYA-HPs' capability, opportunity and motivation to promote health behavior is key to developing interventions to facilitate health behavior advice delivery. The purpose of this study was to firstly, understand factors influencing the provision of health behavior advice by TYA-HPs; and secondly, explore TYA-HPs' preferences for an intervention to facilitate the delivery of health behavior advice in the TYA cancer setting.

Methodology

Participants

Health professionals were eligible to participate if they were in a professional role which involved providing care or advice to TYA cancer patients in the United Kingdom (UK). In accordance with the National Cancer Institute (NCI), the label 'TYA cancer patient' or 'survivor' refers to any young person between the age of 13 and 39 years (inclusive) who is undergoing cancer treatment or has received a cancer diagnosis within their lifetime. Health professionals not involved in direct provision of care or advice (e.g. administrator) or those who work outside of the UK were not eligible to participate.

Recruitment

Participants were recruited through e-mail advertisements sent to several UK-based professional and charitable bodies specializing in TYA cancer patient care. Recruitment advertisements were also distributed to existing contacts within the National Health Service (NHS), London Cancer Network, National Cancer Research Institute Teenage and Young Adult Clinical Studies Group, Teenage Cancer Trust and CLIC Sargent. If participants replied to the recruitment email and indicated interest in participation, they were immediately emailed a 'Participant Information Form'

explaining the format and purpose of study in more detail, alongside further contact detail information. If participants continued to show interest following receipt of both forms, they were immediately invited to interview at a time most convenient to them. TYA-HPs also had the option of choosing preferred interview format (telephone, skype or face-to-face).

Ethical approval

Ethical approval for this study was obtained from the Queen Mary University of London and University College London research ethics committees.

Qualitative interviews

All interviews were conducted by one of four investigators (AP, AP, GP or AC)ⁱ between February and May, 2019. Each interview followed the same semi-structured guide (Supplementary File A) which was based upon constructs of the COM-B model. Interview questions focused on three main themes: (i) TYA-HPs' appraisal of health behavior; (ii) factors influencing TYA-HPs' provision of health behavior advice; and (iii) TYA-HPs' preferences on an intervention to help develop their health promotion skills. A variety of probes were used when necessary and participants were encouraged to share their thoughts and experiences openly. The interview process was audio-recorded on a Dictaphone, anonymized and transcribed verbatim before analysis.

Analysis

Framework analysis was followed according to the protocol outlined by Gale and colleagues¹⁷. Three researchers (GP, AP, AC) independently analyzed seven interview transcripts, each

developing an initial set of codes. An inductive data-driven approach to analysis was taken wherein the codes were grouped into the three components of the COM-B model: capability, opportunity and motivation. The researchers then compared the initial set of codes and identified potential themes to create an analytical framework which was used to code the remaining 19 transcripts. Participants' responses from each interview were summarized and coded into the framework. The quotes within each theme were then independently reviewed and checked by two researchers (AP and AC) to identify common themes and new emerging themes among transcripts. A revised final coding framework was created and quotes for each theme and sub-theme were then collated and summarized by a third researcher (GP). To ensure transparency and ensure the credibility of reporting, the final manuscript was written and cross-checked against the COREQ (COnsolidated criteria for REporting Qualitative research) Checklist ¹⁸.

Results

Response Rate

The exact reach of the recruitment strategy cannot be estimated given that email advertisements were cascaded independently via various professional and charitable bodies. A total of 26 interviews were conducted overall between February and May, 2019. Interviews typically lasted 35 minutes in duration (range of 24 min 42 seconds to 44 mins 6 seconds).

Sample characteristics

Participant characteristics are displayed in Table 1. The professional role and cancer specialty of participants varied and their region of work spanned across the UK. All professions listed within the NHS service specifications for the delivery of TYA cancer care were represented within the study. Participants' years of experience of working with TYA patients ranged from 0.5 to 26 years. Most participants were staff nurses or Consultant Nurse Specialists (CNS) (n=12, n=46%).

Themes

Table 2 displays the four core themes and subthemes which emerged from the interviews. Related to the COM-B model, it was evident that TYA-HPs' reflective motivation to discuss health behavior was to improve patient outcomes and support young people with cancer to foster a holistic sense of ownership over their health. However, personal interest and cognitive biases such as fear of disengaging the patient often affected TYA-HPs' decision to provide advice. Many TYAP-HPs reported low knowledge of and limited skills to address health behavior with patients in their care. It was clear that TYA-HPs' capability to provide advice was limited by lack of available resources and evidence to support health behavior promotion. To promote consistent delivery of health behavior advice, TYA-HPs felt multi-format continued professional development (CPD) interventions should be made accessible to all members of the multidisciplinary team (MDT). Additional quotes relating to each core theme and sub-theme are displayed in Supplementary File B.

Theme 1. Discussing health behavior to support self-management

TYA-HPs cited better patient outcomes (fewer co-morbidities and cancer-related, late-effects and improved quality of life) as the main motivation behind providing health behavior advice. Many TYA-HPs also noted that they discussed lifestyle behavior with TYA patients as a self-management strategy to actively cope and deal with the physical, psychological and social consequences of cancer. Specifically, TYA-HPs often discussed the role of health behavior to support young people with cancer to retain a sense of normality in their everyday life. One health professional described how they used lifestyle behavior as a positive displacement away from the negative elements of treatment and long-term side effects of cancer:

I use it as a way to soften the blow almost. Rather than saying ‘You are going to get a chance of a second cancer or having a heart attack or a stroke,’ I turn it on its head and use health promotion to describe that and then say, ‘The reason it is important to do this, not to smoke and to be active and have... adopt a healthy lifestyle, is because you will be at higher risk of getting A, B and C and this would help you reduce this risk as far as possible.’ (P24)

Some health professionals (predominantly those who were CNSs) noted that their choice to discuss health behavior with a patient was based upon their Holistic Needs Assessment (HNA). Several others also highlighted that, although they may have wanted to discuss health behavior, they wouldn't if it wasn't a topic which was deemed of importance to the young person in their care. This was despite TYA-HPs often noting that these patients were the ones who would benefit most from receiving lifestyle advice. Several health professionals admitted that their decision to provide health behavior advice was due to their own personal interest in lifestyle medicine. Other barriers to discussing health behavior included stigma and fear of alienating the patient, a parent or family being present, and lack of time.

Theme 2. Health promotion within TYA cancer care

Despite health behavior being viewed as important TYA-HPs often reflected that it was not a top clinical priority. For example, one nurse spoke about the need to prioritize treatment-related advice:

In terms of improving all of the side-effects of cancer treatment and all the physical things that can come, and in terms of body image and body confidence, yes. It's massive. [but] all of the things you need to tick off for administering treatment and making sure they're okay and everything, and then adding on a conversation about lifestyle advice is going to be one of the last things on the list. (P22)

When probed, TYA-HPs often discussed that they were not completely confident in their ability to provide detailed or specific advice on health behavior to patients within their care. Most TYA-HPs mentioned that they could provide brief advice on living a general healthy lifestyle but could

not, or did not, feel qualified to answer specific questions about health behavior. Nevertheless, many health professionals noted that working in a multidisciplinary team enhanced their confidence to provide lifestyle advice as they knew they were well supported and could refer the patient to a colleague if necessary.

Other facilitators to discussion included good rapport with patients, patient interest, and engaging with the patients' family. However, the extent to which health professionals felt general health promotion was part of their role varied. Some participants reported confusion if health promotion was their responsibility and uncertainty over whether their colleagues also supported health behavior promotion. This contributed towards a general view of confusion surrounding best practice for health promotion. Some health professionals noted that the expertise of specialist professionals (particularly allied health professionals) was essential, especially for patients who may have complex needs and require tailored support. Health professionals also highlighted the importance of members of an MDT delivering the same consistent message on health behavior to their patients.

Theme 3. Lack of evidence and resources to support health behavior promotion in practice

Health professionals' confusion and conflict over the best advice to provide often stemmed from a lack of specific knowledge relating health behavior to TYA cancer outcomes. Health professionals reported being aware of '*emerging evidence in cancer in general*' with many noting the lack of TYA specific evidence:

There isn't as much evidence to date in the specifically TYA population, but there is a lot of anecdotal evidence that it helps and it makes sense that we should be getting people to [lead a healthy lifestyle].

Health professionals cited study days, twitter, and conference workshops as their core source of information and evidence on lifestyle related topics. Health professionals recall and appraisal of the evidence base was typically quite limited with many unable to recall the source or specific details of the study they had read. Similarly, when prompted on their knowledge of specific health behavior guidelines for young people with cancer many referred to general population health guidance and were not aware of guidelines or statements from professional bodies such as The Childrens Oncology Group or Childrens Cancer Leukemia Group (CCLG). Similar to their discussion surrounding the evidence base, many health professionals noted that guidelines on health behavior tended to be written for the adult cancer population. The same was noted for patient information resources. Many TYA-HPs described referring young people in their care towards guidance written for older adults.

Theme 4. Requirements for implementation and change in practice

In order to change current practice relating to health behavior advice, TYA-HPs were unanimous in their desire for more support to deliver health behavior advice. While some health professionals noted that though they had attended one-off courses or workshops covering lifestyle topics, health promotion was often not covered within most Continued Professional Development (CPD) opportunities. Health professionals expressed a desire for CPD resources on health behavior to be widely accessible and available in multiple formats through E-learning resources, webinars, booklets and one-day workshops. However, some difficulties in using these formats of CPD were noted, particularly whether it was compulsory to attend and finding the time.

For me workshops are better or something with visual learning that I can get involved in and really get to grips with, whereas something like a shared file [e-learning] would be useful for after the training. (P6)

In general health professionals tended to prefer the idea of a CPD resource covering multiple health behavior which contained different levels of information. Information specific to the needs of young people with cancer was viewed as particularly important:

I suspect it probably needs to be a combination, doesn't it? Because I think if we are genuinely looking at lifestyle behaviors in its broadest sense, it almost feels like there are too many things to be putting on one poster or one leaflet or within one thing, [but] they could fit on one thing and then you could use individual resources that sit alongside or underneath that that perhaps offer a greater level of detail [of information] or different strategies. (P11)

Notably health professionals expressed the importance of peer support from colleagues and highlighted the benefit of interdisciplinary sharing of knowledge. Skills-based training on communication and engaging in difficult conversations were highlighted as being particularly useful. Several health professionals noted the value of motivational interviewing, suggesting this may help professionals to develop confidence to pursue conversations about lifestyle and prompt patients to change their behavior. There was a strong feeling that CPD resources need to be evidence-based help reduce uncertainty surrounding the best advice to provide. Suggested content included ‘*facts and figures*’, ‘‘*case studies*’’, ‘*take-home messages*’ and a general ‘‘*research summary*’’. Several health professionals noted that it would also be helpful to share the evidence with young people in their care:

Factual information that I can go to where there are maybe figures that I can take back to patients and say these are the risks, but also these are the places you can go to if you need your own information or your own support. (P6)

Integrating health promotion into care was viewed as challenging. In order to shift health behavior advice delivery from an ‘ad-hoc’ basis to a standard element of practice, most believed that health promotion should be introduced as a professional competency during training. A number of health professionals felt endorsement and backing from leading supportive care and charity organizations specializing in TYA cancer care were essential for widespread access to health promotion materials to be possible. Many health professionals indicated these organizations were also essential for creating change in the culture of care and had the reach to engage health professionals from multiple disciplines. Funding provided by charity organizations for health professionals to do CPD was considered essential to maximize TYA-HPs’ opportunity to take part. Several health professionals also spoke of the importance of patient advocacy. For example, one health professional when describing a preference for CPD support on health behavior noted that *‘the views and the words of young people’* would be the most effective means of raising health professionals’ interest in health promotion. This was echoed by a social worker who highlighted that health professionals working in TYA care are responsive to the needs of their patients:

[If] I just received a flyer that said, ‘Here is a course on this’ and my manager sent it to me, I probably would not pay as much attention to it as if I saw a young person who said, ‘I wanted advice on exercise, but I did not know where to go to get it. (P26)

Discussion

This study aimed to understand TYA-HPs’ appraisal of health behavior, factors influencing whether TYA-HPs provide advice on health behavior to their patients, and TYA-HPs’ preference

on an intervention to help develop their health promotion skills. Findings from this study suggest that although health behavior promotion was viewed as an important element of TYA cancer care, TYA-HPs' ability to address health behavior with patients is limited by lack of evidence linking health behavior to TYA cancer outcomes, TYA-HPs' own biases and perceived clinical priorities, and access to health promotion resources. Mapped to the COM-B model of behavior, these findings suggest that TYA-HPs would benefit from cross multidisciplinary team (MDT) support for improved access to TYA specific resources covering key health behaviors (physical activity, diet, smoking, alcohol consumption and sun safety) and skills-based education and training on delivering lifestyle advice.

TYA-HPs' reflective motivation (i.e intention and choice) to provide lifestyle advice to their patients predominantly stemmed from recognition that leading a healthy lifestyle improves cancer patients' ability to cope and recover from treatment. This included managing side-effects and reducing risk of future cancers or comorbid conditions. TYA-HPs view that health behavior (particularly physical activity) empowers patients to regain control over their health echoes the views of health professionals working within the adult oncology setting ¹⁹. Qualitative data from evaluations of exercise-based rehabilitation programs highlight the role of physical activity-based supportive care in developing self-efficacy and in facilitating a return to normality among both TYA³⁹ and older adult cancer survivors ^{20,21}. However, it was apparent that intrinsic biases regarding patients' interest in receiving lifestyle advice and ability to make lifestyle changes at different stages of cancer treatment influenced TYA-HPs' decision to provide health behavior advice. This is similar to previous studies of health professionals working in the oncology setting ²² and may be addressed by education and training which develops TYA-HPs' clinical reasoning

and self-reflection. In addition, supportive care programs for TYA cancer patients and survivors should incorporate health behavior promotion alongside psychosocial issues such as well-being, relationships, education, and finance which are traditionally addressed ²³.

Similar to our existing quantitative study ⁹, findings from this study indicate that physical activity and diet were the two health behavior topics that TYA-HPs most commonly discussed with their patients. This was partly related to TYA-HPs' own personal interest in these behaviors and perception that these behaviors were of more interest to their patients. Patient treatment status and fear of disengaging also appeared to influence TYA-HPs' decision to discuss health behavior with patients in their care. Akin to existing studies of TYA-HPs ^{24,25} many participants within this study were unsure of the right advice to provide on health behavior and felt confused about whether health promotion was part of their professional role. This finding is consistent among health professionals working with adult cancer patients ²⁶. However, unlike for adult cancer services where there is good evidence linking health behavior to cancer outcomes, the quantity and quality of evidence surrounding the role of health behavior in TYA cancer care is limited ²⁷. Ensuring health professionals have access to the expanding evidence base concerning health behavior in TYA cancer care is essential to allow TYA-HPs to understand the relevance of health behavior promotion to their clinical work.

It was evident that the TYA model of care influenced TYA-HPs' confidence to provide advice. Many TYA-HPs praised the MDT structure and the culture of collaboration. However, some TYA-HPs disclosed that they were confused about whose responsibility general health promotion was within the wider MDT. Given that organizational and workplace culture are known to influence

health promotion behavior in the UK, ^{16,28} efforts should be made to facilitate TYA-HPs to share best practices and garner support from colleagues to address health behavior as a routine task. This could be achieved through social norms-based interventions which have been shown to be effective at changing workplace culture towards smoking cessation ²⁹. Several TYA-HPs highlighted the lack of formal training they had received on health promotion and felt to see change this topic should be included within undergraduate professional training and introduced as a core professional competency. This reflects growing acknowledgement that current medical, nursing and allied health professional curricula need to be adapted to support health promotion ³⁰. Specific to TYA cancer care, the inclusion of general health promotion within the long-term follow-up guidelines is a positive step. Support for the role of health behavior in the TYA cancer pathway should continue to be endorsed at the local and national level by professional bodies (e.g. TYAC in the UK).

Efforts to ensure lifestyle promotion as a routine part of TYA cancer care will be ineffective without resources in place to facilitate and enable TYA-HPs to speak with their patients about health behavior. The findings that lack of resources limit TYA-HPs' delivery of lifestyle advice is reflective of studies conducted among doctors, nurses and allied health professionals working in a range of settings ³¹⁻³³. Efforts should be made to ensure that TYA-HPs have access to both physical and digital information resources regarding health behavior which they can easily hand-out or sign-post patients towards. These may act as prompts to initiate and engage young people with cancer in conversation about their health behavior. This approach (provision of information and very brief advice) has been shown to improve the physical activity levels of adult cancer survivors in the UK ^{34,35}; whether the same approach is effective to improve dietary intake, reduce alcohol

consumption or support smoking cessation remains to be explored. Similarly, integrating health behavior screening as part of the standard holistic needs assessment may also prompt (or nudge) TYA-HPs to initiate a conversation about behavior change. Moreover, in primary and secondary care settings electronic patient record alerts to document smoking behavior have had great traction in prompting health professionals to refer to smoking cessation services. The same principle has been suggested as a potential means to improve the delivery of health behavior advice as part of routine survivorship care during long-term follow-up clinics ³⁶.

TYA-HPs held a strong desire for multi-format TYA specific educational courses, conferences and training to enable evidence-based health promotion. Specifically TYA-HPs were most interested in continued professional development (CPD) opportunities centered on behavior change counseling. Approaches such as the 5As (ask, advise, agree, assist, and arrange for follow-up) and motivational interviewing have shown promise as health professional-centered interventions designed to improve patient behavior in adult settings. No existing published health behavior change intervention for TYA cancer survivors has formally reported taking this approach but existing interventions do highlight the benefit of TYA-HP delivering risk-based counseling and or offering support to set health behavior change goals ³⁷. When probed about the format of CPD delivery TYA health professionals stressed the importance of opportunities for interactivity. There were mixed views on whether face-to-face training or e-learning was most engaging. However, existing research has demonstrated that group training is more effective than web based e-learning with regard to improving professionals' competencies and skills ³⁸. Given TYA-HPs disclosed that they often felt uncomfortable discussing health behavior with TYA patients, activities such as role play and feedback may be particularly beneficial. Quality assurance

processes to guarantee the relevance and credibility and of resources or training was also raised. Charity bodies and professional organizations specializing in TYA cancer service delivery are well placed to provide this kind of input. Similarly, in alignment with principles of engagement and involvement, resources designed to support TYA-HPs to provide lifestyle advice should be developed with input and guidance from the wider TYA cancer workforce. This would also increase awareness and support for the role of health behavior in TYA cancer management.

Limitations

The findings presented within this study extend the current body of knowledge by providing insight on TYA-HPs' perspectives on lifestyle advice delivery. However, there are a number of limitations which must be considered. The purposeful use of sampling methods to recruit TYA-HPs from the UK-based professional networks and charitable bodies means the findings of this study may not be generalized to the whole TYA-HP community in the UK or health professionals working within other countries. Although a reasonable attempt to recruit TYA-HPs of multiple professions was made, given the multidisciplinary and varied nature of TYA cancer services, the sample may not be representative of all TYA-HPs' views. Moreover, due to the design of the study and the heterogeneity of the job roles carried out by each participant, sub-group comparisons of professionals' views was not possible. Similarly, many TYA-HPs work with both TYA patients (those receiving active treatment) and TYA survivors (those who have completed treatment) making comparisons between TYA-HPs' views on how health behavior should be addressed at different time-points difficult. There is also potential that health professionals who are more engaged in leading a healthy lifestyle were more inclined to participate within the study, increasing the likelihood of response bias. In an attempt to reduce researcher bias during the interview process

several members of the research team (GP, AP, AC and AP) conducted data collection. The involvement of more than two investigators in the data coding process and discussion on data saturation was carried out in an attempt to reduce bias within the main findings reported.

Conclusion

This study investigated factors influencing the delivery of health behavior advice to TYA cancer survivors and found that TYA-HPs recognize health behavior promotion as a core part of TYA cancer care but feel ill-equipped to provide advice to patients. TYA-HPs' confidence to provide lifestyle advice to young people in their care could be improved by skills-based training on health promotion; improved access to TYA specific resources and referral pathways and cross MDT support for the role of health behavior in TYA cancer management.

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