



A study of childhood cancer survivors' engagement with long-term follow-up care: 'To attend or not to attend, that is the question'

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ABSTRACT

Purpose: In the UK, there are over 40,000 childhood cancer survivors (CCS); this figure grows approximately 1300 annually. Two-thirds are at risk of developing serious disabling or life-threatening conditions due to adverse late effects of the cancer or treatment received in childhood. Life-long, follow-up care for the surveillance and management of late effects is recommended. This study explored CCS' views and experiences of long-term follow-up (LTFU) care within a cancer centre.

Methods: Paper questionnaires (n = 113) and qualitative interviews (n = 13).

Results: The majority (n = 83, 80%) of CCS reported being satisfied with their LTFU care and felt that it was important to attend long-term survivorship follow-up (n = 97, 86%). However, some were not well informed about their cancer treatment history, purpose for attending the clinic or the potential for late effects. Barriers associated with LTFU included; provision of information, lack of interpersonal relationships, practical and logistic challenges.

Conclusions: Barriers identified can be addressed through strategies including provision of verbal and written information and care plans to increase CCS' knowledge of their cancer history, risk of late effects and the purpose of LTFU care, both at transition and throughout their survivorship journey; patient-centred services that enhance patient choice and flexibility of access to multiple specialities; and use of risk stratified pathways to encourage supported self-management based on cancer type, co-morbidity, and level of professional involvement required. Improving regular provision of information at critical time-points, and exploring a flexible, patient-centred delivery of LTFU care based on risk, could increase attendance and self-management in CCS.

1. Introduction

It is estimated that approximately 300,000 cases of childhood cancer are diagnosed annually worldwide in children and young people under the age of 19, with an estimated 80,000 cancer-related deaths (IARC, 2016; Steliarova-Foucher et al., 2017). The UK has one of the lowest rates of childhood cancer in Europe, with around 1821 new cases in 0–14 year olds (Children's Cancer and Leukaemia Group, 2014) 2630 adolescent and young adults (aged 15–24 years) diagnosed each year; incidence rates have increased over the last decade (Cancer Research UK., 2009). Across Europe approximately 80–84% of childhood cancer patients now reach five-year survival, and around 70% will survive 10 years following end of treatment (Taylor et al., 2004; Gatta

et al., 2008; Cancer Research UK., 2009; Ward et al., 2014). However, long-term childhood cancer survivors (CCS) are at risk of premature mortality or substantial morbidity due to adverse late effects of either the cancer diagnosis or subsequent treatment received (Lackner et al., 2000; Signorelli et al., 2017). The accumulative incidence of late effects also increases with age, with elevated risk for survivorship beyond 35 years often resulting in serious disabling or life-threatening events by 50 years of age (Armstrong et al., 2014). Recent figures suggest that by age 45, 95% of CCS will have a chronic health condition or experience a disabling life-threatening chronic condition (Howard et al., 2018).

Late effects vary depending on the type of cancer and treatment received but can include secondary malignancies, endocrine and metabolic disorders, pulmonary dysfunction, cardiovascular disease,

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infertility, cognitive impairment and disorders of growth development [Bhatia and Landier (2005); Michel et al. (2009); Howard et al. (2018)]. Cancer survivorship is therefore viewed as a distinctive phase of cancer care, and it is essential that appropriate, long-term follow-up (LTFU) of this patient population is conducted to prevent, detect and treat adverse late effects (Edgar et al., 2013; Howard et al., 2018).

Despite evidence, which suggests that LTFU care is beneficial to the long-term outcomes of CCS, there is no conclusive evidence of an optimal healthcare model (Howard et al., 2018). Different models of follow-up care exist for CCS including primary care provided by a family doctor or general practitioner (GP), specialist centre led care, and shared care services. Whatever the health care model for LTFU care, a key time to engage with CCS is at the point of transition to adult services (Freder, 2010; Henderson et al., 2010; Signorelli et al., 2017). Unfortunately, rates of non-attendance at LTFU clinics can vary from 15% (Klosky et al., 2008) to 82% (Iyer et al., 2013). Poor attendance at LTFU clinics has been linked to positive self-perception of current health in adulthood (Cox et al., 2012), experiencing fewer late effects (Klosky et al., 2008; Iyer et al., 2013), wishing to 'draw a line' under their cancer and return to a normal life (Earle et al., 2005), fear of potential late effects from cancer treatment (Michel et al., 2011) and the challenge of attending multiple specialities or appointments (Eiser, 2007). CCS have also expressed barriers and challenges associated with attending clinic appointments, particularly when key information and test results are not available and this may influence a patient's decisions not to attend subsequent appointments (Earle et al., 2005). It has also been suggested that non-attendance may be due to CCS having high levels of self-efficacy in deciding whether to attend (Michel et al., 2011). The aim of this study was to explore adult CCS' reported views and experiences of long-term follow-up survivorship care.

2. Methods

A mixed-method, sequential, explanatory design (Cresswell, 2005) using questionnaires and qualitative interviews examined the views and experiences of CCS of attending long-term follow-up care.

2.1. Setting and study participants

This study took place with CCS who transferred from a regional children's hospital between the ages of 16 and 20 to one specialised bi-monthly LTFU survivorship clinic situated within an adult-focused cancer treatment centre in the UK. The point of transition to the LTFU clinic is a patient-centred process which is primarily age dependent rather than the time since treatment ended. For example, a well patient who was treated for acute lymphoblastic leukaemia at three years of age would transition at the younger end of the age range, whereas a patient treated for a brain tumour aged 15 would typically transition nearer to age 20 years. The clinic is run by both a paediatric and adult oncologist. CCS are initially offered an annual follow-up; the frequency of subsequent follow-up appointments are risk-stratified to meet individual patient need. An alternative telephone based follow up service is offered to patients with fewer needs or those who have a history of non-attendance at face-to-face clinics, although patients can opt back in to the face-to-face clinics at any time.

We recruited CCS aged 18 years and over, who had completed active cancer treatment, and were registered as patients of the long-term survivorship clinic. A study information pack, which included a patient information sheet and paper-based questionnaire, were posted to the home address of all CCS by the clinical team. To gain responses from those CCS that routinely did not attend appointments an additional flyer was sent out mid-data collection to a targeted population of CCS who had not attended clinic inviting them again to participate. CCS were prompted to contact the study team if they had any questions about participation. Participants were invited to send their contact details to the study team on a slip if they agreed to participate in a semi-

Table 1
Interview guide.

1. What is your current age?
2. What type of cancer were you treated for as a child?
3. What type of treatment did you have?
4. How long ago did you finish treatment for your childhood cancer?
5. Do you attend a Late Effects Clinics (LEC) at the hospital or use the telephone consultation service?
6. Do you currently have a treatment/survivorship care plan outlining your follow up care needs?
YOUR VIEWS
7. Do you feel well informed about the purpose of follow up care at the Late Effects Clinic?
8. How important is it to you that you attend regular follow up care at the Late Effects Clinic?
YOUR EXPERIENCE OF APPOINTMENTS AND ATTENDANCE
9. Can you tell me about your experience of attending appointments with the Late Effects Clinics/phone service?
10. Have you experienced any health issues related to your childhood cancer?
11. Is there anything that makes it difficult for you to attend the Late Effects Clinics/phone service?
12. How satisfied are you with your Late Effects Clinics/phone service appointments when you do attend?
13. What do you think could be done to improve the current Late Effects Clinics/phone service?
14. Is there anything else you would like to say about the Late Effects Service or follow up care?

structured interview and were contacted to arrange a convenient time.

2.2. Data collection

The first phase of the study collected structured data using a short, anonymous, self-completed paper-based questionnaire (Nov 2015 and Jan 2016). The questionnaire was developed by the study team, informed by the current literature, clinical expertise and through consultation with eight patients. The questionnaire was divided into three sections which consisted of 19 closed categorical and Likert scale questions and four open-ended response questions. The questionnaire gathered demographic, diagnosis and treatment information, patients' views and opinions of attending long-term follow-up care and knowledge about their cancer treatment and ongoing provision of care. Patients returned the anonymous questionnaire through the post to the study team. A copy of the questionnaire is available from the corresponding author upon request.

Semi-structured interviews gathered more in-depth information on CCS' views and experiences of attending the long-term survivor clinic and knowledge regarding diagnosis, treatment and long-term follow-up. The interview guide questions can be seen in Table 1. Interviews were conducted between Nov 2015 and Jan 2016 by experienced qualitative researchers either via face-to-face, which were conducted at the survivors' homes or via telephone, depending on the patient's preference. Interviews were audio-recorded with the participant's permission and transcribed.

2.3. Analysis

Data from the paper-based questionnaires were entered into IBM SPSS Statistics for Windows (Version 22.0. Armonk, NY: IBM Corp.) Descriptive statistics were used to summarise the closed/categorical and Likert Scale responses structured data (e.g. frequencies and percentages). Analysis of the semi-structured interview data was inductive and adhered to the six key phases outlined in Braun & Clarke's thematic analysis process; familiarisation of data; coding the data; searching for themes; reviewing themes; defining and naming themes and producing the report (Braun and Clarke, 2006). The study team conducted initial analysis on six transcripts and the codes were used as a framework for

developing a coding scheme for the other transcripts. These codes were then grouped into themes and discussed between the study team to define, shape and develop themes.

2.4. Ethics approval

The study obtained ethical committee approval through the authors employing institution [SC21] and approved as service evaluation (using the Health Research Authority decision tool (HRA, 2018) by the participating hospital Trust. Informed consent was obtained from all participants who were involved in the qualitative interviews, consent was implied by those participants returning the questionnaire.

3. Results

The questionnaire was distributed to 458 CCS of which 113 participants returned the questionnaire (25% response rate). The mean age of respondents was 30 years of age (range of 19–70 years). Thirteen CCS (n = 7 male, n = 6 female) participated in the semi-structured interviews by phone (n = 9) or face-to-face (n = 4). The mean age of participants who took part in the semi-structured interviews was 36 years of age (range of 21–71 years). The mean interview duration was 30 min, with individual interviews ranging from 11 to 55 min. Respondents received treatment for a range of childhood cancers which are presented in Table 2. Most received a range of treatments consisting of chemotherapy, radiotherapy, surgery, and bone marrow transplants or a combination of each of these treatments. The majority of participants that responded to the paper-based questionnaire reported accessing the LTFU service through physical attendance at the clinic (n = 92, 84%). Only seven (6%) respondents used telephone services alone and 11 (10%) respondents reported attending the clinic as well as using telephone services.

The key findings from the questionnaires and interviews are presented together under three themed headings: (i) motivation for attending long-term follow-up care and (ii) knowledge of cancer treatment and potential late effects. (iii) suggested improvements to the current service. All quotes or open comment are represented as a questionnaire respondent (QR) or interview respondent (IR).

3.1. Motivation for attending long-term follow-up

The majority (n = 83, 80%) of CCS reported being satisfied with their LTFU care and felt that it was very important to attend long-term survivorship follow-up (n = 97, 86%). The interviews explored reasons as to the importance associated with long-term follow-up as well as factors that motivated CCS to attend clinic. CCS discussed that attendance at follow-up enabled them to access health information about

late effects that they had either experienced or may have been experiencing at the time.

'I only see him every 3 years sort of thing. If anything's built up over that time I can go what's this, what's that, what's that ... its little things with me, it's more moles, its family planning sort of things. It's little things like that that I need information on' (IR 1)

Specialist information provided by the clinical team were valuable to CCS who reported receiving inadequate expertise, resources and information outside of their specialist services.

'It's your opportunity to talk to somebody that understands about your particular situation, I find that a lot of doctors, simply don't really understand.' (IR 7)

Some CCS discussed reasons for attending the clinic which included feeling indebted to their doctors for their childhood cancer treatment and attendance allowed them to express this gratitude.

'I've been very lucky to survive because I had very advanced, you know, cancer, so that's probably one of the reasons why I go, is to sort of, repay the doctors for, you know, the care they did, the care they gave me'. (IR 12)

Not all CCS felt motivated to attend. Some discussed how the initial letter, at the point of transition inviting the patient to the LTFU clinic could have been considered a barriers for attending.

'To be honest if you think you are provided with a letter, saying, you know we are monitoring for late effects of a horrible cancer you had previously, it's not the nicest thing.' (IR 11)

Many (n = 9) of the CCS interviewed reported mixed emotions following attendance at the clinic. Feelings experienced included; anxiety or slight apprehension prior to an appointment as a result of any late effects experienced or relapse of disease.

'I mean I do get a little bit panicky sometimes but, as I always worry that they're going to tell me, another, you know, late effect that they've found, that I could be at risk of ... because I've had the heart and I've had the eggs, so I think what's the next one going to be ... always get anxious when I get my bloods done, just in case my blood count shows anything.' (IR 12)

These feelings were often followed by a sense of relief and reassurance that they were no subsequent concerns following attendance at their appointment.

'If anything it's a nice reprieve, especially as occasionally you start over thinking things. I haven't been for a while, what if this, what if, so it's nice ... to go in and have a check over and kind of clear your mind a bit.' (IR 13)

Table 2

Type of childhood cancer treated.

Type of childhood cancer	Questionnaire respondents n (%)	Interview participants n (%)
Leukaemia (cancer of the blood e.g. Acute lymphoblastic leukaemia, Acute myeloid leukaemia)	22 (20%)	2 (15%)
Lymphoma (cancer of the immune system e.g. Hodgkin Lymphoma, Non-Hodgkin Lymphoma)	28 (25%)	4 (31%)
Solid tumour		
The response categories selected were:	53 (49%)	7 (54%)
● brain/spinal/CNS tumour (n = 35, 32%)		
● kidney/renal tumour (n = 9, 8%)		
● soft tissue sarcoma (n = 7, 6%),		
● cancer of the bone' (n = 1, 1%)		
● missing (n = 1, 1%)		
Other:		
● Aplastic Anaemia (n = 1)	7 (6%)	0
● Thyroid cancer (n = 2)		
● Optic glioma, Melanoma (n = 2)		
● Wilms tumour (n = 1)		
● Ewing's sarcoma (n = 1)		

Despite the majority (n = 97, 86%) of CCS in the study feeling motivated to engage with long-term follow-up services, many encountered barriers to attending clinic which included; the burden of travelling long distances to attend clinic visits (n = 48, 48%) as well as co-ordinating appointments around work commitments (n = 43, 36%). Many of the CCS had experienced co-morbidities which created difficulties and posed challenges in having to attend multiple appointments at different sites with different specialists. More complex patients were keen to see services streamlined where multi-disciplinary professionals were working more collaboratively.

“it would be good, to have all the specialists in one place in one day so that people can get it all over and done with, ... and then he'd [consultant] see more people as well, because if they've got loads of clinics to go to, they [patients] won't want to bother.” (IR 8)

3.2. Knowledge of cancer treatment and potential late effects

In the survey some CCS acknowledged they did not feel well informed regarding the rationale for attending the LTFU clinic (n = 24, 21%) nor about the late-effects risks they may face (n = 44, 41%) in the survivorship period. Interview participants expanded on this saying they did not remember being directly given any literature about why they should attend the clinic or their potential late effects.

‘I've never really been given literature or anything as to why I attend, or not that I'm aware of anyway. It's just, I understand I've got to go for check-ups every x amount of years just to make sure I'm still doing ok so that's the extent of my sort of understanding ... I've never had any paperwork or literature explaining what the reason is behind, you know, what they're looking for.’ (IR 2)

Information relating to treatment and potential late effects were often provided to parents at the time of diagnosis and treatment. There were often not relayed to the child or were discussed several years ago and therefore the information was not retained in many cases.

‘I do think they did tell me what I was at risk of but I can't remember because it was quite a few years ago. You would be better asking my mum on that one as she knows she has all of her files still.’ (IR 13)

One CCS decided to ask the nurse about her original treatment and was provided with information that she had not previously known:

‘I found out it was combination chemotherapy because I thought it was like just one and I found out it was actually three. I found out that the tablet they'd given me to help stop my periods, they'd actually given me too high a dose and that's why I went through the change. I found out quite a lot that I didn't actually know, that nobody had explained to me.’ (IR 10)

One CCS became distressed during the interview when she spoke of a late effect that she had not previously been aware of and was a direct consequence of her childhood cancer treatment.

‘I developed, well, what I know now to be (name of late effect) which was probably from the chemotherapy but I didn't know that that's what it was ... But it's never, ever been explained to me. It's just turn up and see how you are and then send you off again [at the clinic] ... I finally went back and my consultant said, oh yes, ...you will have had that from the radiotherapy. So that really upset me, because no one had ever said and no one had told me to expect that.’ (IR 11)

In relation to knowledge about treatment and late effects both questionnaire and interview participants were asked whether they had a treatment/survivorship plan. Most questionnaire respondents indicated that they had not received a treatment/care/survivorship plan (n = 72, 66%) or were unsure if they had one (n = 29, 27%). Only eight respondents (7%) reported having a follow-up care plan in place.

3.3. Suggested improvements to the current service

The interviewees who used the Late Effects clinic and telephone service were also asked what they felt could be improved. One CCS felt that they should be treated in clinic with more consideration of their individual circumstances:

‘If there was one thing that I wished that they did differently, ...I wish they'd treat each person a little bit differently you know, as to how it's affected them, not as a whole.’ (IR10)

Another CCS spoke of how the name ‘Late Effects Clinic’ could be interpreted as ‘scary’:

‘I personally, I think they might need to change the name I think that would just scare people to be honest.’ (IR 11)

One CCS spoke about the use of technology to provide reminders given the long gap between appointments:

‘I mean, the only thing is that they give you the appointment for the next two years on a card and you've got to keep this card safe for two years So it would be nice if you got, you know a text.’ (IR 12)

Several of the CCS had multiple co-morbidities which can lead to many face-to-face appointments at different sites for check-ups. These more complex CCS were keen to see some streamlining in the way the multiple professionals worked together:

‘I'd love it to be everything all in one day, check out my heart, kidneys, have the specialists there or the, you know, able to go and get x-rays, or scans, echo scans things like that all on one day, and do a sort of like MOT of your body in one day.’ (IR 5)

One CCS felt that each patient should be able to choose whether they attend the face-to-face clinic or a telephone clinic for each of their appointments:

‘I think it might be easier if people when they get the appointment, they should be able to say whether they want to go to the clinic or if they need a phone consultation.’ (IR8)

Another CCS felt that it would be greatly beneficial to have some continuity of service in regards to the staff they see during appointments:

‘I keep seeing different people when I attend clinic’ (QR12)

It was highlighted by some of the CCS that they were not completely clear of the reason that they were to attend the LEC and highlighted a need for written information regarding the purpose of the late effects appointments:

‘I've never really been given literature or anything as to why you know, why I attend, It's just, I understand I've got to go for check-ups every x amount of years just to make sure I'm still doing ok so that's the extent of my sort of understanding ... I've never had any paperwork or literature explaining what the reason is behind, you know, what they're looking for.’ (IR 2)

Some CSS discussed a need for the information about late effects to be reiterated periodically:

‘I was 22 (age at interview 43) when I was told what might happen, and I feel like I'd like to be told again, and if they know any more now, because that was a long time ago and do they know what has happened to other people and what might happen to me and, I don't feel, I feel, I'm not sure how well informed I feel really.’ (IR 5)

Another CCS felt a little confused as to exactly why they were attending the clinic:

‘Unsure of what I should be getting out of these appointments and unaware of how much or little they are aware of my case. Not aware of any plan or information of what my long term effects could be?’ (QR 103).

4. Discussion

The aim of the National Cancer Survivorship Initiative is to “ensure that those living ... beyond cancer get the care and support they need to lead as healthy and active a life as possible” (<http://www.ncsi.org.uk>). Our findings highlight further work that needs to be conducted in this area to ensure that informational, interpersonal, and practical factors are considered if CCS are to receive the information and appropriate services to meet their specialised needs. For CCS to engage in LTFU care their information needs and motivations need to be acknowledged and addressed. Our findings indicate that a key influencer regarding the decision to attend LTFU care is the information and knowledge a CCS receives about their cancer treatment, risk of late effects and on-going care. The CCS who receives limited information regarding late effects consequences and has a poorer understanding of their treatment history, seemed less likely to engage in the LTFU clinics or services available.

Despite recommendations for changes in practice to improve information offered to CCS including treatment summaries and survivorship plans (Singer et al., 2013), our findings support existing literature which shows that many CCS continue to report poor levels of knowledge (Kirchhoff et al., 2014; Lindell et al., 2015; Quillen et al., 2017). Most CCS in this study (93%, n = 101) either did not have any form of care/survivorship plan or were unsure whether they ever had a plan in place. This may be due to the majority of survivors having completed treatment more than five years ago. Our findings also indicate that parents are often the primary source of information regarding their child's cancer treatment. Difficulties can arise when this information is not passed from parent to child or when cancer treatment is complete and the child enters into adulthood without their prior cancer history. The provision of written information at key intervals such as at transition, including provision of treatment summaries or survivorship care plans are all important components in ensuring that CCS have adequate knowledge and understanding of their previous diagnosis, treatment and the potential late effects of their cancer treatment (Lindell et al., 2015; Quillen et al., 2017). Despite various approaches to improve engagement within healthcare systems globally and nationally, the current study, as reported elsewhere (Quillen et al., 2017; Howard et al., 2018), suggests further improvements are required to ensure provision of adequate information at key intervals of the CCS journey. Simple steps such as reviewing and revisiting important cancer information verbally and in writing when a child transitions into LTFU care can increase CCS understanding of their diagnosis, treatment, and late effects and potentially enhance their motivation to attend LTFU for ongoing surveillance and management.

CCS should be asked about the level and type of information they desire, how satisfied they are with the information received, and be provided with regular opportunities to voice their needs and concerns. Information tailored to the preferences of the CCS are important in ensuring supportive care is appropriate and meaningful to the individual. The personal information recollection regarding their historical treatment or their recollection of what they been told about potential late effects can vary dramatically between CCS. One way this can be achieved is to inform CCS about the aims and benefits of long-term follow-up and how decisions about care and treatment are jointly negotiated and agreed over time. The provision of treatment care-plans can assist CCS to keep up-to-date with information about their condition, as well as providing the patients with relevant and timely information. Communication in the domain of long-term follow-up care can be managed through Macmillan's recovery package interventions targeted at self-management opportunities, quality of life issues, as well as financial and work concerns (Macmillian Cancer Support, 2015a).

Although engagement in long-term follow up may increase anxiety to some CCS by discussions centred on the patient's previous diagnosis and treatment, many CCS expressed benefits from attending long-term follow up care. Survivors in our study felt motivated to attend LTFU

clinics as they provided reassurance, following monitoring, that things were ‘okay’, in addition to having access to information and specialist staff. Some patients expressed feeling indebted to the health service and their treating multidisciplinary team and therefore attended LTFU clinics to express their appreciation.

However, CCS, could be dissuaded from attending LTFU clinic appointments if they had to navigate competing speciality appointments alongside employment and family commitments. The challenge of attending multiple appointments for CCS has been documented in the literature (Howard et al., 2018; Granek et al., 2012) and seem to persist despite calls to improve the co-ordination of survivorship care with tailored follow up pathways and holistic packages of support which address issues of complexity of needs and self-management (Independent Cancer Taskforce, 2015a, 2015b). Some of these barriers can be overcome by addressing organisational considerations, whether simple measures like tele-health clinics or the use of mobile applications for those who are unable to physically attend clinics (Baseman et al., 2017) or more significant re-structuring to offer age-appropriate, multidisciplinary, one stop clinics (Gan, 2014) with multi-disciplinary professionals at one clinic, which may be of particular value for those considered to be at highest risk of serious or multiple late effects. The decision for CCS to attend LTFU appointments is not simple and is influenced by a process of weighing up multiple motivations and priorities against each of the challenges presented.

The CCS who participated in this study represents a small select group of patients who are registered with the LTFU service. However, despite all efforts by the study team, only one non-attender expressed their views in the open-ended section of questions in the paper-based questionnaire. Further efforts to engage with non-attenders is needed to explore their reasons as well as to further identify methods for improving follow-up care in this patient cohort.

In conclusion, this study reports on some benefits and barriers experienced by CCS in relation to LTFU care. Barriers presented included CCSs' lack of knowledge in relation to their cancer treatment history, the potential benefits associated with LTFU care, as well as the impact of organisational and practical barriers which may include multiple and competing appointments, as well as the location and timing of appointments. These barriers may be addressed through cancer service strategies based on improving information discussed and disseminated, use of care-plans, offering care closer to people's homes, nurse-led clinics and telephone follow-up. Other strategies may involve; remote surveillance such as tele-health and patient portals, and through risk stratified pathways to encourage supported self-management based on cancer type, co-morbidity, and level of professional involvement required (NHS, 2016). Earlier and more frequent supportive care interventions (NHS England, 2016) may mitigate the impact of late effects in CCS based on enhanced co-ordination and integration of services, empathetic communication, shared decision-making, and a focus on psychological and physical wellbeing throughout the disease trajectory. The use of holistic needs assessments in clinical practice (Macmillian Cancer Support, 2015b) may also assist with identifying unmet psychological needs and emotional concerns in CCS associated with fear, anxiety and depression.

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Declaration of competing interest

The authors declare there are no conflicts of interest for this study.

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