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Providers' Perspectives of Survivorship Care for Young Adult Survivors of Childhood Cancer

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Abstract We examined healthcare providers' perceptions of the goals of survivorship care and survivor programs, systems-level barriers and individual patient-level barriers to engaging patients in survivorship care, and potential resources for increasing engagement. In 2012, we recruited 21 healthcare providers of young adult survivors of childhood cancers from a children's hospital and a cancer center in the Southeastern USA to complete telephone-based semi-structured interviews. The sample was 45.95 years old (SD= 7.57) on average, 52.4 % female, and 81.0 % MDs. The major goals of survivorship programs identified were medical care management (e.g., addressing late and long-term effects, providing survivorship care plans (SCPs), assisting in transition of care) and holistic care including addressing psychosocial issues and promoting healthy lifestyles. Systems-level barriers to engagement in survivorship care included limited resources (e.g., time), role confusion (e.g., within cancer centers, from treatment team to survivorship care, role of primary care providers), communication challenges within the medical system (e.g., limited tracking of patients, lack of understanding of the role of survivorship clinic), communication challenges with patients (e.g., setting expectations regarding transition to survivorship care), and lack of insurance coverage. Perceived patient-level factors included psychological barriers (e.g., fear, avoidance), resistance to survivorship care, and physical barriers (e.g., distance from survivorship clinics). Resources to address these barriers included increased access to information, technology-based resources, and ensuring valuable services. There are several systems-level and patient-level barriers to survivorship care, thus requiring multilevel interventions to promote engagement in care among young adult survivors of childhood cancer.

Keywords Childhood cancer · Survivorship care plans · Transition to survivorship · Young adults

Introduction

Long-term survival for pediatric cancer has increased to nearly 80 % [1, 2]. The increasing incidence and decreased mortality from childhood cancer have resulted in a growing population of survivors at increased risk for health problems and early mortality often in young adulthood [1, 2]. The available literature describes the variety of long-term and late medical effects that can develop and persist among individuals diagnosed and treated for cancer during childhood and adolescence [3–8].

Over the last decade, cancer survivor programs have been formed to assess and treat long-term effects and potential late effects of therapy. For pediatric cancer survivors, follow-up care usually begins 2 years after completion of cancer therapy or 5 years after the initial cancer diagnosis [9]. Most patients are then followed annually. Ultimately, childhood cancer survivors typically transition to adult survivorship clinics at 21 years of age. The goals of cancer survivor programs are multifaceted. A major goal is the treatment of long-term effects, early detection of late effects of cancer therapy, and the

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Highlights • Young adults face many barriers to engaging in the requisite survivorship care.
• Greater communication and role clarification among providers should be promoted.
• Earlier integration of survivorship programs is needed.
• Systems- and patient-level barriers to care require multilevel interventions.

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timely medical treatment of those sequelae to ultimately improve quality of life and decrease complication-related healthcare costs [10].

The Institute of Medicine (IOM) report *From Cancer Patient to Cancer Survivor: Lost in Transition* stresses the need to promote communication and coordination among healthcare providers treating diverse health problems within the cancer survivor population (e.g., depression, sexual dysfunction, heart disease). It is critical to promote prevention and surveillance of new and recurrent cancers and other late effects and interventions for health problems secondary to cancer and its treatment (e.g., pain and fatigue; psychological distress; concerns related to employment, insurance, and disability). In 2012, the American College of Surgeons Commission on Cancer required accredited cancer centers to issue survivorship care plans (SCPs) to every cancer patient posttreatment (to be accomplished in 2015) [11]. According to the IOM publication, key elements of SCPs include descriptions of recommended follow-up and surveillance (i.e., adherence to recommended follow-up, screenings, and appointments), advice on maintaining and improving health, information on employment and insurance, and the availability of psychological and support services [12].

Despite the importance of continued evaluation, cancer survivors often become lost to follow-up. This is a particular risk among young adults who transition to survivorship care or make the transition to adult survivorship programs. Young adults are at particular risk for lack of awareness of and adherence to medical treatment recommendations due to multiple factors [13] including issues related to insurance coverage [14] as well as avoidance or disengagement in healthcare due to the trauma of the cancer experience [15, 16], increased independence from parents in making medical decisions as young adults [14], and high mobility during these transitory years [13]. Ultimately, many young adult cancer survivors may not be aware of the health risks or recommended follow-up and surveillance for survivors or may lack access to follow-up care. Thus, a proportion do not receive the recommended follow-up care necessary to achieve optimal health.

The current study was aimed at understanding healthcare providers' perceptions of the goals of cancer survivor programs, challenges in transition of care from pediatric survivorship to adult survivorship clinics and to PCPs, systems-level barriers to engaging patients in survivorship care, perceived patient-level barriers to engaging patients in survivorship care, and potential resources for increasing engagement in cancer survivorship programs. Specifically, we interviewed healthcare providers (e.g., oncologists, nurses, nurse practitioners, social workers) who address childhood cancer survivors before and after the transition to survivorship and adult survivorship programs.

Materials and Methods

Participants and Procedures

Study procedures were approved by the [deleted for blind review] Institutional Review Board; the procedures were in accordance with this entity's ethical standards (IRB# 00055570). The current analyses are part of a larger mixed methods study conducted in 2012. We conducted surveys and semi-structured interviews among young adult survivors of childhood cancers and semi-structured interviews of healthcare providers of young adult cancer survivors. This paper presents results of the latter. Semi-structured interviews are well-suited to explore individual subjective experiences and attitudes, particularly related to concepts or phenomenon that have not been well explored previously [17]. Thus, this qualitative approach was selected due to the limited prior research related to the focus of this study.

We recruited healthcare providers of young adult survivors of childhood cancers from a university-affiliated children's hospital and a National Cancer Institute-designated cancer center in the Southeastern USA. Our research team identified providers at both institutions representing those who provided care to childhood cancer survivors during treatment and those providing care to patients once treatment was completed in the context of survivorship care in either the pediatric setting or in the context of a young adult cancer survivorship program. All participants had prior experience working with those aged 18–21, as those in the pediatric setting worked with patients transitioning into young adulthood and those in the adult setting worked with those transitioning into their care. Those in the regular cancer center also had experience providing for older young adult cancer survivors. Those working in "other" settings had connections to one of the centers but had a primary appointment in a separate setting (e.g., an affiliated hospital or clinic). Research staff called and emailed potential participants to provide information about the study, indicating that it consisted of a 30- to 45-min telephone-based, audiorecorded interview. Of the 30 providers identified, 21 (70.0 %) providers consented and completed the interviews. No compensation for participation was provided.

Measures

A trained MPH-level interviewer facilitated the interviews. Prior to beginning the structured interviews, participants were read an informed consent and provided oral consent. They were then asked to respond to a range of questions regarding sociodemographics, their training, and nature of their work. They then began the interview which was guided by a semi-structured interview guide developed and pilot tested by our authorship team. The discussion guide focused on various topics, including (1) providers' perceptions of the goals of survivorship programs (e.g., "What does your healthcare organization do to address survivorship care? What are the basic goals of survivorship care in your clinic? To what extent do you think these goals are being met? What other issues does your healthcare organization address in survivorship care?”); (2) challenges in transition of care from pediatric survivorship to adult survivorship clinics and to PCPs (e.g., “What are the specific challenges you face in the process of patients transitioning from pediatric cancer care to young adult survivorship care?”); (3) systems-level barriers to engaging patients in survivorship care (e.g., “What needs do you think are not being met in the context of your current survivorship care, if any? What barriers come up that make addressing these issues difficult? How have these events impacted your patients’ ability to engage in the appropriate care? What issues have come up with insurance that have had implications for your patients’ continued care?”); (4) individual patient-level barriers to engaging patients in survivorship care (e.g., “When you think about your experiences with your patients, what are some of the obstacles that have come up in terms of them arranging or keeping appointments? What life changes have you seen impact your relationship with your patients?”); and (5) potential resources for increasing engagement in survivorship programs (e.g., “What resources might be helpful in promoting patients to make and follow through with appointments? What might help maintain connections with patients over the long term? What communication channels might be helpful?”).

Data Analysis

Participant characteristics were summarized using descriptive statistics. Qualitative data were analyzed according to the principles outlined in Morgan and Krueger [18]. Audiorecordings were transcribed verbatim by a professional transcriptionist, and NVivo 10.0 (QSR International, Cambridge, MA) was used for text coding and to facilitate the organization, retrieval, and systematic comparison of data. Transcripts were independently reviewed by the lead author, the second author, and an MPH graduate student to generate preliminary codes. They then refined the definition of primary (i.e., major topics explored) and secondary codes (i.e., recurrent themes within these topics) and independently coded each transcript. The independently coded transcripts were compared, and consensus for coding was reached. Two independent coders then coded all interviews using the refined coding tree. Upon completion, an MPH-level staff member and one of the coders came to a consensus about coding in disagreement. The final codes were then used for analysis. Themes were identified, and representative quotes were selected.

Results

Table 1 provides sociodemographic, educational, and practice-related characteristics of the study participants. The sample was an average of 45.95 (SD=7.57) years of age, 52.4 % female, and 71.4 % White/Caucasian. Most (81.0 %) were MDs, with roughly 15.45 years (SD=7.18) of practice and 16.76 years (SD=7.29) of experience working with cancer survivors. Primary specialties included hematology and oncology, radiation oncology, medical oncology, etc.

Below, we outline the major topics covered, the primary themes that emerged, and some secondary themes. We also present representative quotes for each primary and secondary theme.

Goals of Survivorship Programs

When asked about the major goals of survivorship programs, a major focus was on medical care management, including addressing late and long-term effects, providing SCPs, and assisting in transition of care.

One provider said,

> I think in general our focus has been on cancer-related and non-cancer-related complications that are either risks that result from the cancer itself, and that being treated or cured, and the actual treatments that are given to do that, so for instance, treatments like radiation or chemotherapy that could affect the endocrine system or cardiovascular system, or there might be additional complications.

Another reported,

> They get a treatment plan guideline that all of our cancer survivor patients get after [they finish treatment], you know… it’s a comprehensive report that is made out by the team, and then there’s also a pretty comprehensive raw report that is printed out in a kind of a follow-up letter to the physicians.

Another statement reflecting this theme was,

> I think our cancer survivorship program does a very good job in taking over the patient care and then also informing primary care docs, not just the oncologists but also the actual pediatricians, about how the patient’s doing, and then making that good transition to the adult facility, or adult care.

Another theme that emerged was a holistic approach to care, including promoting mental health, healthy lifestyles, and planning for the future.

Table 1 Participant characteristics

Variable	*M* (SD) or *N* (%)
Age (SD)	45.95 (7.57)
Gender (%)	
Male	10 (47.6)
Female	11 (52.4)
Race/ethnicity (%)	
White/Caucasian	15 (71.4)
Black/African American	1 (4.8)
Hispanic/Latino	1 (4.8)
Asian/Asian American	2 (9.5)
Other	2 (9.5)
Educational background (%)	
MD	17 (81.0)
NP	2 (9.5)
RN	1 (4.8)
Social worker	1 (4.8)
Number of years in practice (SD)	15.45 (7.18)
Number of years working with cancer patients/survivors (SD)	16.76 (7.29)
Primary specialty (%)	
Pediatric hematology oncology	13 (61.9)
Pediatrics, other	1 (4.8)
Radiation oncology	1 (4.8)
Medical oncology	1 (4.8)
Hematology and oncology	5 (23.8)
Location (%)	
Cancer center	6 (28.6)
Children's center	8 (38.1)
Both	1 (4.8)
Other	6 (28.6)
Primary work with cancer patients (%)	
During treatment	3 (14.3)
Posttreatment	1 (4.8)
Both	17 (81.0)

One participant reported,

> The whole psychosocial aspects of survivorship care are addressed by a team approach of our psychiatrists and social workers, and clinicians to try and help readjustment into the psychosocial aspects that are associated with completing cancer therapy and returning to usual activities.

Another said,

> I think for some families, there's a lot more time spent on reassurance. I think families are a lot more focused on being concerned if the cancer's coming back, and so there are definitely some visits where I feel like I spend more time with that than really focusing on the goals of providing them good education and follow-up in terms of healthy bodies, healthy lifestyles, and those sorts of things.

Systems-Level Factors Influencing Engagement in Survivorship Care

When asked about barriers to promoting engagement in survivorship care, a major theme that emerged was limited resources. This included time/resource constraints and difficulty in coordinating appointments/inconveniences, both of which had implications for the logistics of transitioning care.

For example, one participant reported,

> We have such a high volume of patients that we are going to see 30-40 patients in one clinic. You can't sit there for an hour and listen to them.

Another participant noted,

> The survivor clinic is quite full, and so when you have a person, who's not motivated to go to survivor clinic, and they can't get in at a convenient time for them, or it takes months, they lose interest in it. I see that a lot. I have a patient that called three times—well, we can't get you into this clinic, there's been a change and we have to reschedule you—they're finished with the survivor clinic then.

Another major theme was role confusion. This included confusion about roles between oncologists and survivorship programs; confusion about roles between survivorship programs and PCPs; and continuity and comprehensiveness of providers.

One participant indicated,

> There are two transitions here. One is transitioning from being treated as a cancer patient to a cancer survivor, but the other transition going on at the same time is oftentimes being transferred from a pediatric care to a family practice/OB/GYN/internal medicine group, so it's a double hand-off, and it's going to be interesting how it all works. There's no set pattern here for having a young adult survivorship group within the department of pediatrics, so I'm not too sure how it's going to work out. My goal is to take care of the patient's cancer-related risk factors either directly, or at least inform their primary care physicians these are the risk factors and these are

> recommendations for future studies for these patients. It's interesting.

Relatedly, another recurrent theme was communication challenges within the medical system. Some issues that emerged included no or limited tracking or monitoring of patients' other appointments and a lack of provider awareness of what is being done in the survivorship clinics.

In reference to tracking patients, one participant said,

> In our system, we don't get any such prompts for anything that's missed, so if a patient doesn't come for an appointment, I don't get a flag that they didn't come.

Regarding awareness, a participant said,

> I don't entirely know what is being addressed in Survivor [Clinic]. We don't know what services and resources are being provided….

Related to communication challenges with patients, there were also concerns about overwhelming amounts of information provided to patients and not setting expectations regarding transition to a survivorship clinic.

One participant reported,

> If you've graduated to Survivorship Clinic, things are good, and then if you walk in and hear 'you might develop heart disease and you might develop this,' all things that they need to know but the presentation is very critical on how you're able to give that in a way that's not overwhelming and frightening. Families have trust in who their providers are and now they're switching to somebody new. If they hear all this stuff and they haven't heard it before, then it can be somewhat unsettling and then that can be a barrier to them wanting to go back, obviously.

In terms of setting expectations regarding transition of care, one participant noted,

> Once again, I think we should try to introduce the whole idea of survivorship sort of earlier in the process so that it's not sort of an afterthought of 'okay, now you survived, so now we're going to send you to survivorship', which in a sense is what we're doing. We need to make it more of a continuum from day one.

Finally, a major institutional factor that was discussed was lack of access to insurance coverage for young adults, particularly once they become ineligible for their parents' insurance.

Perceived Patient-Level Factors Influencing Engagement in Survivorship Care

In terms of perceived patient-level factors influencing engagement in survivorship care, participants mentioned psychological barriers such as fear of what patients might learn at survivorship or avoidance of hearing about medical complications.

One participant indicated,

> I think one of the barriers to participation in Survivor Clinic is fear on the part of families. For the last year, I've been working hard when I've been referring families to try and minimize the impact of that, but I suspect it gets back to them indirectly through the social networks. They hear about another family's first visit to survivor clinic, and some of the parents, especially mothers, leave those first visits absolutely terrified.

Relatedly, participants reported resistance to survivorship care, specifically related to feeling healthy and seeing no need for follow-up or having a preference of seeing their initial cancer care providers.

One participant reported,

> One of the things I've heard from many families is 'we're not really excited about going to see a survivor clinic. We want to come back and see the provider that… you know, they want to come back to you because they've worked with you for the last two or three or four years, and 'we'd rather just stay with somebody we know.'

Another said,

> The hard thing I guess is that so many of them are quote unquote doing great. They don't have obvious deficits. They don't have obvious medical issues and so it's really hard to persuade them or their parents that they're in any way special. I think they sort of figure well, I used to have cancer and now I don't. Now I'm normal. That's all I need to know.

Another theme was physical barriers, such as moving away as a young adult, distance from survivorship clinic, or lack of time.

One participant said,

> When you live six hours away and you don't have transportation and you have to work hard to get up here for a whole day of appointments, that's one more reason not to come.

Resources to Promote Engagement

When asked about potential resources for promoting survivorship care, a major theme involved supporting patient access to information, including patient education, a clear map or set of recommendations for continued care, and greater access to medical records, both for patients and providers.

One participant reported,

> Our electronic medical records system could be made so much more transparent, that it would make it easy to resolve some of these issues. So for instance, in some electronic medical records systems, the patient can log into a website and see a lot of their own information, simple stuff like when their next appointment is and which appointments have been passed, and if that same information were available to me, I could tell if a patient I've referred to [the] Survivorship [Clinic] had followed up, and the electronic medical records could flag me if they didn't follow up, and then some action could follow.

Participants also suggested the need for additional financial resources to support continued care, with two participants mentioning a need for more financial support from nonprofits during the posttreatment period.

One participant noted,

> I just feel like for some of these patients are taken care of until they are 21 and a lot of times it's like they are kicked off because they don't have insurance anymore and the clinics won't see patients that they have taken care of, so I felt that there needs to be something written that we can't just drop these kids because they turned 21, and they aren't able to work, they can't get insurance, but yet they have had healthcare up until now, and then bam, and then they are going to ER and this and that for their primary care.

Addressing another patient-level barrier, participants suggested technology-based strategies and other strategies to address challenges related to distance or moving.

One participant said,

> I think that's what speaks to this generation, anything that is in the form of a video game, in the form of social media, in the form of, you know, the Twitter, the Tumbler, anything electronic to get the message to them. I think that's how we reach this generation.

Another theme that emerged was ensuring provision of a range of services that are valuable to patients. For example, participants felt that fertility/reproductive services and that more comprehensive wellness care, involving health behaviors and mental health, needed to be integrated more into survivorship care to enhance its value to patients.

Discussion

The current study focused on the perspectives of healthcare providers regarding the goals of survivorship care for young adult cancer survivors and challenges to achieving engagement in survivorship care among this population. Unique information and data consistent with prior research were obtained regarding providers perceptions of the goals and functions of survivorship programs, organizational or institutional-level barriers to engagement in survivorship care, and individual patient-level barriers to engagement in survivorship care.

In terms of perceived goals of survivorship care, participants were in agreement about their most relevant roles. This is not surprising given that half of these participants had a specific function or role in posttreatment care of cancer survivors. The most commonly cited goals were medical care management and a holistic approach to care involving psychosocial issues. These functions have emerged more recently with the report *From Cancer Patient to Cancer Survivor: Lost in Transition* highlighting the need for SCPs to address these issues.

Regarding systems-level factors that challenge engagement, many of the findings of this research resonated with prior research findings [14, 19–21], particularly those related to time and resource constraints, the cumbersome nature of providing SCPs and aiding in transition, issues with insurance coverage, and some issues with lack of knowledge regarding the functions of survivorship care. As such, these findings support the impact of these barriers in the current context of cancer survivorship care. In addition, our findings add to the current literature by highlighting additional barriers. Two major related themes were role confusion and communication challenges. In terms of role confusion, this entailed confusion about roles between oncologists and survivorship programs and confusion about roles between survivorship programs and primary care providers. Regarding communication challenges within the medical system, there was a lack of communication among providers and challenges in continuity and comprehensiveness of providers. In addition, difficulty making referrals to PCPs and uncertainty of what happens with PCPs was mentioned.

In relation to communication challenges with patients, participants suggested a need to set expectations regarding transition to survivorship clinic and greater capability of tracking or monitoring of patients' other appointments. In addition, providers indicated a need to provide patients with information in consumable ways that might reduce or mitigate patients' levels of fear and anxiety. Given these challenges, a great deal of work must be done to examine what processes best support the transition of cancer survivors, ensure that those supporting cancer survivorship have the requisite training and knowledge, support communication and monitoring of progress among healthcare providers, and integrate survivorship care into treatment in order to facilitate the transition.

There was a range of perceived individual patient-level barriers to engagement in survivorship care. Participants mentioned fear of what patients might learn at survivorship or avoidance of hearing about medical complications [15, 16], which was also highlighted by practitioners in terms of determining a more effective communication strategy in relaying health information to survivors. A major question that must be addressed is "How do we provide comprehensive and accurate information to survivors in a palatable and meaningful way?" Work is needed to address this important question. Similarly, the issue of promoting the value or creating greater value to survivorship care is an important one to consider, along with the preference to continue to see the healthcare providers with whom they already have a relationship. Introducing the idea of cancer survivorship care and the program earlier on, potentially during active treatment, might facilitate this. In addition, examining the functions that survivorship programs could provide that would be valuable to survivors is critical. Young adult cancer survivors need information about their treatment and future risk for late and long-term effects and other health-related information. It is important to know what resources or support they might need to motivate them to continue survivorship care so that these issues can be addressed in their entirety. This is particularly true given that, once they feel better, they may be particularly unmotivated to engage in follow-up care. Finally, moving away as a young adult or distance from survivorship clinic were seen as barriers to continued engagement in survivorship programs, which has been documented previously [13].

Ultimately, these findings indicated that the Chronic Care Model [22] (CCM) is an appropriate framework for survivorship care, particularly within the young adult population. The CCM addresses the shortcomings of standard chronic disease care [23] and is highly relevant to cancer survivorship [24]. The CCM is comprised of six elements (organization of healthcare, clinical information systems, delivery system design, decision support, self-management support, and community resources) interacting together to promote productive interaction between an "informed, activated patient" and a "prepared, proactive practice team." Clinical information systems are established to provide timely and accurate information about patients (e.g., disease registry). The CCM also requires modifications of the delivery system design, replacing acute care visits with more effective alternatives such as proactive telephone-based assessments, counseling, and other approaches. Decision support refers to the evidence-based protocols upon which the care team bases their treatment decisions. The CCM envisions a patient-centered approach to disease management affected by self-management (SM) support. This support includes appropriate education, skills training, psychosocial support, and setting goals and priorities. Community resources refer to voluntary agencies and civic programs and prescription reimbursement. This is particularly relevant, as participants suggested the need for additional financial resources to support continued care, including insurance coverage and non-profit organizations expanding their purview to include supporting survivors posttreatment.

The current study has important implications for research and practice. Future research is needed to examine the processes that best support cancer survivorship care and evaluate current systems in place for doing so. Multilevel interventions addressing the range of systems-level and patient-level barriers should be developed and tested. In practice, greater communication is needed among healthcare providers and patients in order to ensure that referrals are provided and followed up on and to ensure that all providers (and patients) are clear on the roles they are playing throughout the process of follow-up care. Moreover, there is indication that introducing survivorship care early in the cancer treatment process might help set expectations and comfort patients as they transition to survivorship. In addition, greater resources are needed in the clinical setting (space, financial support) and external to the clinical setting, such as technology-based tools or wellness programs, to increase engagement in cancer survivorship among young adult survivors of childhood cancers. Finally, a patient-centered approach to care is essential in ensuring that survivorship care is addressing issues that are valuable to patients.

Limitations

This study has some limitations. First, this was a qualitative study of 21 healthcare providers representing various training and practice backgrounds recruited from one pediatric hospital and one cancer center. Thus, findings from this small sample may not generalize to other institutions and is not likely exhaustive of the range of practitioners in these contexts or more broadly. In addition, the interviews may not have yielded exhaustive information regarding the constructs and processes investigated. In particular, this manuscript does not include data from our mixed methods study involving surveys and interviews with young adult cancer survivors, which is presented in a separate manuscript. Additional qualitative and quantitative research is needed to confirm and elaborate on these findings.

Conclusions

Findings from this study support prior research indicating barriers to young adult survivors of childhood cancers engaging in the requisite survivorship care, including institutional time and resource constraints, limited or no insurance coverage for this population, fear and/or avoidance among patients to return to care, and moving and/or distance as a barrier to engagement. This study expands the literature by qualitatively describing the challenges related to communication among providers, role confusion, and the need for earlier integration of survivorship programs into treatment. Providers also indicated the need for additional resources in the clinical setting (space, financial support) and external to the clinical setting, such as technology-based tools or wellness programs, to increase engagement in cancer survivorship among young adult survivors of childhood cancers.

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Conflict of interest The authors declare that they have no competing interests.

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