Emotional Changes and Experiences of Parents with Cancer Following CLIMB[®] Program: A Pilot Study

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Abstract

When a parent raising a child develops cancer, he/she faces difficulties in continuing the parental role. For parents to face their own cancer treatment with peace of mind, supporting them in reducing challenges related to the parental role and promoting communication with their children is essential. This pilot study was designed to implement the Children's Lives Include Moments of Bravery (CLIMB[®]) program for cancer parents and determine quality of life (QoL), psychological anxiety, and parents' emotional changes/experiences. This study analyzed the changes in scores for QoL and psychological anxiety before and after participation in CLIMB[®]. The changes perceived by the parents were examined qualitatively and descriptively through semi-structured interviews. There were five participants (four mothers and one father). Their mean age was 48 ± 7.0 years. QoL increased from 63.4 ± 4.1 (63.0) to 69.2 ± 5.1 (70.0) points. On the subscale, emotional changes/experiences increased significantly from 16.6 ± 3.1 (16.0) to 20.4 ± 3.2 (20.0) points (p = 0.04). Psychological anxiety, measured using the State-Trait Anxiety Inventory (STAI), decreased for both state and trait anxiety (p = 0.04). After participating in CLIMB[®], parents recognized their own hard work and felt less guilty about their children. In the parent-child relationship, parents and children were able to face cancer together and communicate their feelings to each other. It is essential to continue to intervene to promote communication between parents and children.

Keywords: cancer, CLIMB[®] (Children's Lives Include Moments of Bravery) program, communication, parents who have cancer, QoL, STAI,

1. Introduction

In recent years, the number of cancer patients raising children has increased, and support is needed. According to cancer statistics from the US Surveillance, Epidemiology, and End Results (SEER) Program, an estimated 10.4% of newly diagnosed cancers in the US are among people aged 18–55, and 22.4% of all patients diagnosed with cancer are aged 21–55 (Howlader et al., 2015). Similarly, In Japan, there are approximately 56,000 patients per year with children under the age of 18 (Inoue et al., 2015), or about 6% of all cancer cases. These families may represent a small number of cases, but given the psychological importance of childhood in adult mental health, cancer patients raising children should be researched and their needs identified.

A parent with cancer who is raising a child may have difficulty continuing the parental role (Akagawa, Makabe, Ito, Kimura, & Andoh, 2021) and may be hesitant to tell the child about his/her own cancer (Kuswanto, Stafford, Sharp, & Schofield, 2018). For parents to face their own cancer treatment with peace of mind, supporting them in reducing difficulties related to the parental role and promoting communication with their children is vital. One way to support parents with cancer and their children is through the Children's Lives Include Moments of Bravery (CLIMB[®]) program. CLIMB[®] was developed by the US Children's Treehouse Foundation (2022); it is a support program for parents and children that aims to empower "children and enhance their ability to cope with the stresses

associated with parental illness." In the program, children learn about cancer treatment and express their feelings through crafts. Parents are free to discuss any topic with their healthcare providers. There have been several scattered reports of the effectiveness of CLIMB[®], and Kobayashi, Heiney, Osawa, Miwa Ozawa, and Matsushima (2017) suggest that participation in the CLIMB[®] program in Japan improves the QoL of parents with cancer who present with post-traumatic stress symptoms. O'Neill, O'Neill, and Semple (2019) found that providing opportunities to talk about cancer can help minimize future psychosocial problems. In a recent study, children's participants were highly satisfied with the program (Akagawa et al., 2022) and had higher QoL and self-esteem scores post-intervention. However, there is little up-to-date information on the effects on parents. In addition, while the children's program has fixed content, the parents' program is basically a free discussion of topics. Therefore, the impact on parents needs to be evaluated, as it is likely to depend on the relationship between participants and facilitation by the health care provider. From an evaluation perspective, it is also essential to consider how parents perceive changes in their children due to CLIMB[®]. This study focuses on the changes in the children as perceived by their parents, in addition to parent's QoL and psychological concerns. We believe that if we can identify the effects and challenges for parents, this will contribute to more appropriate future parental involvement.

The purpose of this study is to evaluate parents' participation in the CLIMB[®] program in terms of QoL, psychological anxiety, and parents' emotional changes/experiences. The research questions are:

- (1) How do parents' QoL and psychological anxiety change before and after the program?
- (2) What are the parents' emotional changes/experiences?

2. The CLIMB[®] Program (Akagawa et al., 2022)

CLIMB[®] denotes "Children's Lives Include Moments of Bravery." Participants are patients undergoing cancer treatment who have children in elementary school.

The purpose of CLIMB[®] is to help children tap into their own strengths and increase their ability to cope with the stresses associated with parental illness. CLIMB[®] is a structured program carried out in closed groups. After confirming the attendance of parents and their children, they are moved to separate rooms. Children take part in the program together with staff (Table 1). The children's section of the program has three goals: (1) learn how to express one's feelings; (2) learn how to communicate one's feelings to those around oneself; and (3) learn to cope with one's emotions. Feelings are dealt with in each session, and participants interact with others in the same situation through crafts and cancer education. Parents discuss issues with medical staff. Discussion topics are openended and set as topics that participants would like to discuss.

The program is generally held six times every other week, with each session lasting 2 hours. Still, for the study, the program was consolidated to four times every other week, with each session lasting about 2.5 hours, due to poor transportation access in the region and to coincide with children's long vacations.

The CLIMB[®] program staff members include facilitators who have attended the facilitator training course held by the non-profit organization (NPO) (HopeTree, 2008). Facilitators at parent meetings provide a warm and welcoming atmosphere for participants to express their thoughts and feelings. They listen to participants' thoughts about their cancer treatment and concerns about communicating with their children. Facilitators try to find commonalities among the parents attending the parent meeting to alleviate feelings of loneliness and to enable communication among them. They also introduce the children to the type of programs they are doing.

	A stivity seel	Feeling	Activity	
	Activity goal	of the day	Activity	
1	Decrease isolation by sharing one's cancer story with other children and learn about feelings, using "happy" as an example	Нарру	"All about me"	
			To help the children self-disclose feelings about their parent's illness, make sense of the event, and build cohesion and increase trust among the children.	
2	Increase the children's knowledge of cancer and its treatment	Confused	"What is cancer?"	
			Share your feelings of confusion. Learn about cancer.	
3	Normalize feelings of sadness	Sad	"Feeling mask"	
			Making masks to express sad feelings. Sharing feelings of sadness.	
4	Assist the children in identifying strengths and normalizing anxiety	Scared	"Strong Box"	
			Create a box that expresses your strengths. Decorate the box with a representation of what you like and your strengths to overcome fear and anxiety. Share with everyone about your strengths.	
5	Assist the children in expressing and managing anger in healthy ways	Mad	"Anger cube"	
			Share feelings of anger and write anger and stress management strategies on dice.	
6	Facilitate communication with the parent who has cancer	Feelings for parents	"Get well card"	
			Write a get well note to your parent with cancer.	

Table 1. Content of the CLIMB® program for the children's group (Akagawa et al., 2022)

3. Method

3.1 Study Setting and Participants

The study's design is a pilot study and interview. The target population consists of patients undergoing cancer treatment in Japan who have children of elementary school age. The condition for participation in the program was that the parents must have told their children about their cancer. Parents were excluded if they had a high psychological burden before program.

The CLIMB[®] program was held in August 2019. Beforehand, the study's purpose was explained to the parents. After their consent was obtained, they were asked to complete a questionnaire survey before and after CLIMB[®]. Semi-structured interviews were held with respondents whose consent was obtained after the completion of CLIMB[®]. Interviews were conducted in a private room and lasted about one hour per person.

3.2 Instruments for Data Collection

Prior to CLIMB[®], the respondents were asked about their gender, age, and cancer type as attributes. The following questionnaire was administered before and after CLIMB[®].

The QoL of cancer patients was measured using the Functional Assessment of Cancer Therapy Scale General (FACT-G) developed for cancer patients (Cella et al., 1993). It consists of 4 subscales and 27 items: 7 physical items, 7 social/family items, 6 psychological items, and 7 activity/functional items. Each item is rated from 0 to 4 on a 5-point Likert scale; the higher the rating, the better the QoL. The use of the FACT-G scale is increasing rapidly worldwide, and the reliability and validity of the Japanese version has been established (Shimozuma, 2001). In order to use it, the developer performed a prescribed use registration procedure and obtained permission to use it.

Anxiety was measured using a new version of the State-Trait Anxiety Inventory (STAI) (Hidano, Fukuhara, Iwawaki, Soga, & Spielberger, 2000) based on Spielberger's STAI (Spielberger, Gorsuch, & Lushene, 1970) to measure individual state and trait anxiety. There are 40 questions in total. State anxiety has 20 items and refers to anxiety that applies to the individual at that very moment. The rating is based on a 4-point scale ranging from "not at all applicable" to "very applicable." Trait anxiety has 20 items and refers to anxiety that applies to one's usual

and everyday self. The 4-point scale from "almost never" to "almost always" is used. Each item ranges from 1 to 4 points, but because some items have reversed numbers, the total score ranges from 20 to 80 points.

In the semi-structured interviews held after CLIMB[®], we asked about (1) how the parents felt their children had changed; and (2) changes the parents observed in themselves.

3.3 Analyses

Simple tabulations were made for individual attributes. Each item was scored for QoL and psychological anxiety, and changes were checked at two-time points: before the program started and immediately after it ended. Pre- and post-intervention evaluations were compared using the Wilcoxon signed-rank test. JMP 15.2 was used for statistical analysis.

The semi-structured interviews were transcribed verbatim based on the recorded data and notes, and codes were generated by summarizing the parts on (1) how the parents felt their children had changed and (2) the changes the parents observed in themselves. Categories and subcategories were generated by examining similarities. In order to enhance the study's reliability and validity, it was reviewed by two researchers from the coding stage onward. The analysis was supervised by a researcher skilled in qualitative research methods. In addition, we asked the participants who took part in the interviews to provide feedback on the analysis.

3.4 Ethical Considerations

This study was approved by the ethics committee of the author's university (Approval #2262). For clinical trial registration, we registered the study with the University Hospital Medical Information Network (UMIN) in Japan (Registration #UMIN000043504).

The study was explained to the participants in writing. The content consisted of the following: (1) the research background, objectives, and techniques; (2) methods used to protect personal information; and (3) when publishing the results, no personally identifiable information should be released. In addition, the questionnaire informed the participants that palliative care physicians and clinical psychologists were available to respond to questions about any physical or mental health challenges. After the explanation, consent to participate was obtained. The program was provided free of charge as an honorarium for this research.

4. Results

CLIMB[®] was held in August 2019. One facility participated in the study. Five individuals responded to the questionnaire survey, including three who took part in the interviews.

Demographic data are shown in Table 2. There was one male and four females. The parents' age, based on the mean \pm standard deviation (median), was 48 ± 7.0 (48); the average age of their children was 9.1 ± 1.8 (9.0). The cancer types were breast, pancreatic, and colorectal. The parents' medical conditions were stable during CLIMB[®]. None of them changed their treatment plans or the hospitals where they were receiving treatment.

ID	Parental role	Age	Cancer type	Children's age
1	Mother	48	Breast	7, 10
2	Mother	40	Breast	7, 9
3	Mother	55	Pancreatic	9
4	Father	55	Colorectal	12
5	Mother	42	Breast	10

Table 2. Participants' characteristics

Table 3 depicts QoL, and Figure 1 portrays the pre- and post-intervention changes in the total score for QoL. The total score, in terms of the mean \pm standard deviation (median), increased from 63.4 \pm 4.1 (63.0) before the intervention to 69.2 \pm 5.1 (70.0) afterward, but the difference was not significant. Significant increases in the subscale were seen for emotional changes/experiences, which rose from 16.6 \pm 3.1 (16.0) to 20.4 \pm 3.2 (20.0) (p = 0.04).

QoL		Pre	Post	D volue	
		Data	data	I -value	
Dhygical health	$Mean \pm SD$	5.0 ± 1.2	4.8 ± 0.8		
r hysical health	median [IQR]	5.0 [4.0, 6.0]	5.0 [4.0, 5.5]	0.32	
Social/family	$Mean \pm SD$	20.6 ± 2.1	22.4 ± 3.0		
Social/family	median [IQR]	20.0 [19.0, 22.5]	22.0 [19.5, 25. 5]	0.06	
Emotional	$Mean \pm SD$	16.6 ± 3.1	20.4 ± 3.2		
changes/experiences	median [IQR]	16.0 [14.0, 19.5]	20.0 [18.0, 23.0]	0.04*	
Eurotional	$Mean \pm SD$	21.2 ± 2.2	21.6 ± 2.1		
Functional	median [IQR]	20.0 [20.0, 23.0]	21. 0 [20.0, 23.5]	0.41	
Total	$Mean \pm SD$	63.4 ± 4.1	69.2 ± 5.1		
10(4)	median [IQR]	63.0 [60.0, 67.0]	70.0 [64.0, 74.0]	0.07	

Table 3. QoL comparison before and after CLIMB[®] N = 5

Wilcoxon signed-rank test. *p < 0.05.



Figure 1. QOL for parents (FSCT-G) total score

Table 4 outlines the STAI scores. Figure 2 (state anxiety) and Figure 3 (trait anxiety) present the pre- and post-intervention changes in terms of the total STAI scores.

Table 4. STAI comparison before and after $\text{CLIMB}^{\textcircled{B}} N = 5$

STAI		Pre	Post	
STAL		data	data	· I -value
T-4-1-4-4	$Mean \pm SD$	43.8 ± 2.0	32.6 ± 5.5	
Total state anxiety	median [IQR]	43.0 [42.0, 46.0]	31.0 [28.0, 38.0]	0.04*
	$Mean \pm SD$	45.0 ± 3.5	40.4 ± 5.1	
lotal trait anxiety	median [IQR]	46.0 [41.5, 48.0]	39.0 [36.0, 45.5]	0.04*

STAI: State-Trait Anxiety Inventory Wilcoxon signed-rank test. p < 0.05

The total score for state anxiety, in terms of the mean \pm standard deviation (median), decreased from 43.8 ± 2.0 (43.0) before the intervention to 32.6 ± 5.5 (31.0) afterward (p = 0.04). The mean \pm standard deviation (median)

of the total score for trait anxiety decreased from 45.0 ± 3.5 (46.0) before the intervention to 40.4 ± 5.1 (39.0) afterward (p = 0.04).



Figure 2. STAI (Total state anxiety) total score



Figure 3. STAI (Total trait anxiety) total score

Table 5 presents the changes parents perceived in their children. There were five categories:

- My children have become more understanding and empathetic toward my feelings.
- My children have begun to communicate negative feelings to me.
- My children now understand my cancer treatment and the side effects.
- When my children have concerns, they now ask me questions about my cancer treatment and recovery.
- My children have started to actively help me with household chores.

Categories	Subcategories		
My children have become more	My child said to me, "Mom, you've been through a lot."		
understanding and empathetic toward my feelings.	My child began to tell me "It must have been hard" and "It must have been painful" in regards to chemotherapy.		
	They started caring about me when I went to the hospital.		
	When I was in treatment and feeling down about not being able to fulfill my role as a parent, my child empathized with me, saying she understood how I felt.		
	On a particularly difficult day during my cancer treatment, my child rubbed my back and hugged me, reminding me that I wasn't alone.		
My children have begun to	Recently, my child started telling me about bad things that happened at school.		
communicate negative feelings to me.	My child told me about being bullied at school.		
	My child told me, "I knew dad's treatment was hard, so I held back what I wanted to say."		
My children now understand my cancer treatment and the side effects.	When my child saw a real IV, he said, "Mom, so this is how you always get treated."		
	The child was learning that sometimes, oral anti-cancer medications can be difficult to handle.		
	For the first time, my child understood that cancer is not contagious.		
When my children have concerns, they now ask me questions about my cancer	My child began to ask me about my treatments and tests. For example, "What have you done today?"		
treatment and recovery.	My child said she wants to see my breast cancer surgery scar from a year ago and asked me if it hurt.		
	I was surprised when my child asked about the length of my hospital stay and my future treatment schedule.		
	My child asks me when I feel sick or have a difficult time feeling better.		
My children have started to actively help me with household chores.	After my breast cancer surgery, my child said, "I know your arm must hurt, so I'll help you with your luggage."		
	During the week I was sick and unable to move after chemotherapy, my child said, "I know you can't move now," and helped me with my chores.		
	My children have begun to think and act about what they can do.		

Table 5. Changes in the children as perceived by their parents

Table 6 presents changes the parents observed in themselves. There were five categories:

- I've learned to accept myself.
- I am now able to have open conversations with my children about my medical condition and treatment.
- I no longer have to keep my cancer diagnosis a secret from my children, and I have also let go of the guilt that I used to feel about it.
- I am now able to listen to my children's thoughts without holding back.
- I have started to feel that our family can work through challenges as a team.

Categories	Subcategories		
	When my child said to me, "You did your best," I realized, "Oh, I did my best."		
	When my child touched my surgical wound, the tension there was alleviated.		
	I hadn't realized how hard I had been working, but when the hospital staff told me I was doing well enough, I felt saved.		
I've learned to accept myself.	I used to blame myself for not being a good parent, but now I can be kinder to myself and recognize my efforts.		
	I could relate to the feelings of other parents in similar situations, and this helped me to be more compassionate toward myself.		
	After my surgery, I realized that sharing my experience with others who will undergo surgery in the future could help them prepare for what to expect.		
I am now able to have open conversations with my children about my medical	I used to avoid writing "exam" appointments on my calendar because I didn't want my children to become anxious, but now I am comfortable sharing this type of information with them.		
condition and treatment.	I am now able to have open and honest conversations with my child about the treatment plan, including the potential side effects.		
	I feel relieved that I no longer have to keep things hidden from my children.		
I no longer have to keep my cancer diagnosis a secret from my children, and I have also let go of the guilt that I used to	I used to feel guilty for keeping [my cancer] a secret from my kids, but now I am able to be honest with them about it.		
feel about it.	I used to tell my children that it wasn't hard, but now that I am honest with them about the challenges, I feel more at ease.		
I am now able to listen to my children's	Now that we are more open with each other and no longer have to keep things hidden, I am able to listen to our children's feelings more attentively.		
thoughts without holding back.	I used to feel apprehensive about asking my children about their thoughts because I was worried about their reactions. But now, I realize that I don't have to be afraid to ask.		
I have started to feel that our family can	Our mutual trust has been strengthened, and we now feel less uncertain about the future.		
work through challenges as a team.	Our family bond has become stronger and I feel like I can get through anything.		

Table 6. Changes in parents themselves

4. Discussion

This study aimed to evaluate a program for parents undergoing cancer treatment based on QoL, changes in psychological anxiety, and parent-child perceptions. As a result, emotional changes/experiences on the parental QoL subscale increased significantly, and anxiety decreased significantly. CLIMB[®] enabled the children to gain accurate knowledge about their parents' cancer and to express their own feelings. The parents also recognized their own hard work and no longer felt guilty about their children. In the parent-child relationship, they are now able to communicate their feelings to each other.

4.1 Changes in QoL and Psychological Anxiety

In this study, CLIMB[®] increased parents' QoL. However, in a previous study, Akagawa et al. (2021) found that parents' QoL was higher before the intervention than during cancer treatment. There are two possible reasons for this outcome. One is that the group reported few physical symptoms from the subscale scores. Cancer treatment decreases QoL (Yoshida & Kanda, 2016) and leads to the loss of the parental role in patients raising children (Akagawa et al., 2021). However, the participants had no physical symptoms, which can be considered due to their high QoL. A second possible reason is that they all had told their children about their own cancer. According to Zhang et al. (2022), parents tend to withhold information about their own cancer from their children and delay telling their children about it. In addition to not wanting to burden their children, parents believed that telling their

children the truth would have a negative impact. Furthermore, the children revealed that they find it difficult to understand the facts. In Japan, parents may also underestimate their children's resilience (Iwata, Kumagai, & Saeki, 2020). However, parents and children both feel burdened when parents do not tell their children about their cancer. For example, parents may feel guilty for hiding things, and children may experience physical and mental stress (Hauskov Graungaard, Roested Bendixen, Haavet, Smith-Sivertsen, & Mäkelä, 2019; Stefanou et al., 2018). In addition, trust in the parent-child relationship may decrease when the diagnosis is not discussed. This study's participants affirm that parents who believe in their children's abilities to cope with stress and tell their children about their own cancer will improve the parent/child bond and reduce the psychological burden caused by parents' concealment. This is evidenced by the significant increase in the emotional changes/experiences on the QoL subscale.

Trait and state anxiety before the start of CLIMB[®] were higher than the Japanese standard (Nakazato & Mizuguchi, 1982), and the patients were highly anxious. However, anxiety significantly decreased after CLIMB[®] and reached the norm. In addition, transient trait anxiety was reduced, and state anxiety—which can be said to represent individual characteristics—was reduced as well. It is thought that the sources of parental anxiety are diverse; these include the shock of being diagnosed with cancer, anxiety and stress about treatment and the future, the conflict over whether or not to tell the child, and the difficulty in communicating with the child after telling him/her. There is also concern that by telling children about their parents' cancer, the people around them will find out (Yoshida et al., 2010). At CLIMB[®], parents in the same situation shared their feelings with other parents and discussed their concerns with the medical staff, which is believed to have helped alleviate their anxiety. In addition, children who participated in CLIMB[®] had less negative feelings about their parents' cancer (Akagawa et al., 2022), which may be a contributing factor.

4.2 Parents' Perceptions of Changes in Their Children

As for the changes in their children that the parents perceived, the children may empathize with the parents; this is considered to be a form of emotional support for cancer treatment. In the case of the child beginning to communicate negative feelings, it seems to be an opportunity to reaffirm the value of being a parent by being depended on as a parent. When children understand cancer, they will feel able to face cancer together with their parents; this will also reduce parents' sense of loneliness (Akagawa et al., 2021).

One of the changes the parents observed in themselves is that they are now able to view themselves in a more positive light. In addition to their relationship with their children, their own treatment experiences may be helpful to others; this may have changed the way they perceive their cancer. In their interactions with others, as well as with children who have participated in CLIMB[®], the parents are able to act as role models and to envision their future selves (Akagawa et al., 2022).

Second, there were changes in parent-child communication. Communication between parents and children whose parents are ill tends to be negative (Huizinga, Visser, van der Graaf, Hoekstra, & Hoekstra-Weebers, 2005) and closed (Cho, Yoo, & Hwang, 2015), mainly because parents tend to avoid answering questions about their illness in front of their children. The mutual relationship between parents and children changed due to their participation in CLIMB[®] as both parents and children faced cancer together.

4.3 Clinical Implications

Cancer patients raising children prioritize communicating with their children about their cancer (Sinclair et al., 2019). CLIMB[®] was a useful form of support for the parents. However, there is a need for useful, practical, and easily accessible resources for assistance (Sinclair et al., 2019). CLIMB[®], which the author organized, is held twice a year and is not regionally accessible. The gap in that support needs to be filled. Currently, the Children's Treehouse Foundation (2022) has developed an online psychosocial group support program for children and parents/guardians participating in CLIMB[®]. It is necessary to utilize this system to ensure that support is consistently available everywhere. In addition, it is importance for parents that their children's mentally and physically remain stable (Akagawa et al., 2021). Since CLIMB has been proven to be effective in improving children's quality of life and mental health (Akagawa et al., 2022), it is important to continue CLIMB with children as well.

In addition, the anxiety and conflicts that cancer patients face while raising children have already begun by the time they are diagnosed with cancer. There is a need to help parents reach social resources and support as quickly as possible when they are diagnosed with cancer. To this end, it is essential to enhance early screening regarding psychosocial aspects of cancer care at hospitals. In particular, it is vital to establish a system to collect information on family structure and the parent–child relationship at the time of the cancer diagnosis and to provide information

on how to communicate with children before treatment begins. This will prevent cancer patients who are raising children from suffering as patients, from feeling alone in their struggles as parents, and will help build a relationship in which the family can overcome the subsequent battle with the disease together.

4.4 Limitations

At the start of this study, the novel coronavirus (COVID-19) pandemic had started in Japan. At many sites, the CLIMB[®] sessions were cancelled or postponed. Since then, it has been difficult to have face-to-face CLIMB[®] sessions. Therefore, although the number of participants in this study was small, the data were valuable as a pilot validation. The small number of participants did not allow for analysis of differences by cancer type or parental role. In addition, parents' concerns and anxiety are likely to differ based on each child's age. We need to continue building upon our survey findings to capture parents' characteristics.

5. Conclusion

CLIMB[®] significantly increased parents' emotional changes/experiences on the QoL subscale and significantly reduced psychological anxiety. Parents recognized their own efforts and felt less guilty about their children. In the parent-child relationship, parents and children were able to face cancer together and communicate their feelings to each other.

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Competing Interest Statement

The authors declare no competing or potential conflicts of interest.

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