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Returning to school from the perspective of adolescent cancer survivors: a qualitative analysis

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ABSTRACT

Objectives: to understand the dynamics of returning to school from the perspective of adolescent cancer survivors. **Methods:** a qualitative study was conducted using symbolic interactionism as a framework. Fourteen adolescent cancer survivors undergoing outpatient treatment at a hospital specializing in childhood cancer in the city of São Paulo participated in the study. Semi-structured interviews were used, and thematic analysis was employed to analyze the data. **Results:** four themes were identified: *Not telling anyone about having cancer; Suffering bullying at school; Facing prejudice;* and *Seeking normality*. Adolescent cancer survivors face a series of personal challenges after completing treatment, including returning to school, due to difficulties caused by prejudice — either because of their physical appearance or the stigma of the disease itself. **Conclusions:** the dynamics of returning to school from the adolescents' perspective reveal a mixture of difficulties faced, coping strategies, and the desire to get on with life like everyone else.

Descriptors: Adolescent; Cancer Survivors; Return to School; Neoplasms; Pediatric Nursing.

INTRODUCTION

The diagnosis and treatment of cancer bring about changes in the lives of children and adolescents(1). In addition to the physical burdens caused by therapy, patients face an abrupt disruption of their daily lives, being disconnected from their friends, family, social life, and school environment. These disruptions can have lifelong psychosocial and socioeconomic consequences(2).

The number of child and adolescent cancer survivors has been steadily increasing across the world, exceeding 80%(3,4). These are individuals who have had cancer and remained disease-free for at least 5 years(4). They require long-term follow-up to monitor for late effects, as they may experience: a second cancer; organ and tissue disease; growth and development disorders; learning and memory issues; social and psychological maladjustment; and changes in mood, feelings, and behavior(3). Assessment and follow-up should be long-term, focusing on the persistent physical and psychosocial effects related to treatment, as well as how survivors experience and adapt to them(1,3,4).

Adolescence, understood as the age range between 12 and 25 years(5), and young adulthood consist of crucial moments for changes in psychological, social, and physiological development, with an expected transition to independence(6,7). Experiencing cancer interferes with normal development and personal growth, often negatively affecting various aspects of psychological, functional, and social well-being(7).

Cancer significantly impacts social life, education, and interaction in the school environment(8-10). The educational experiences of children and adolescents during and after cancer treatment are impaired or even interrupted, leading to negative psychosocial consequences(8,11). Once treatment is complete, returning to school activities is an important step in the lives of adolescent survivors of childhood cancer.

Returning to school aims to improve the quality of life of these adolescents, reduce distress, lessen isolation, and promote self-esteem among cancer survivors(8). Most childhood cancer survivors are able to return to the educational system; however, an unsuccessful return can increase the risk of social isolation and stigmatization. Survivors who have experienced this challenge describe the experience as stressful and lonely(8,12).

Currently, rehabilitation efforts are increasingly being employed in pediatric oncology wards to support patients' transition back to their daily routines as early as possible, with the aim of minimizing the damage caused by school and social absences(3).

Sensitive, welcoming, informative, and personalized support can help adolescents cope with the complexities of their lives and encourage them in their educational progress(10,11). However, little is known about how returning to school after cancer treatment influences adolescent development, self-identity, and social relationships(12,13). The support of health professionals is important for the reintegration of these adolescents into school life. Thus, the objective of the present study was to understand the dynamics of returning to school from the perspective of adolescent cancer survivors.

METHODS

This qualitative study employs a secondary interpretative approach(14,15), to understand the dynamics involved in adolescent cancer survivors' return to school. The secondary analysis originated from a primary study that sought to understand the experience of childhood cancer survivors. Through this interpretative analysis of the data, it was possible to understand the strategies used by adolescent cancer survivors to return to school after the end of treatment. This systematic approach aimed to go beyond a description, seeking to obtain resources for a more thorough understanding of the process of school reintegration for these adolescents(15,16).

To guide the study and seek to understand the phenomenon of cancer survivors returning to school, symbolic interactionism (SI)(17) and thematic analysis (as a methodological framework)(18) were employed. Symbolic interactionism aims to understand the cause of human action and how individuals act in relation to their definitions and beliefs. It focuses on the nature of interactions, the dynamics of social activities between people, and the meaning of events for individuals in the world they inhabit, in their everyday natural environments, and in the actions they perform(17).

Symbolic interactionism is considered an interpretive science, a psychological and social theory that aims to represent and understand the process by which humans create and attribute meaning to the reality in which they live(17). The choice of this theoretical framework enables the exploration of interactions between the parties from a social perspective.

Thematic analysis(18) is a method for identifying, analyzing, and reporting themes (patterns) emerging from the data, which allows them to be organized and described in detail, also implying the interpretation of various aspects related to the research topic(18).

In preparing this manuscript, we considered the criteria for reporting qualitative studies outlined in the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist(19).

Data collection for the primary study took place from March 2018 to January 2019, through individual interviews. The participants were 14 adolescent cancer survivors, aged 12 to 22 years, who were followed up at the outpatient clinic of a public hospital specializing in pediatric oncology in the city of São Paulo. Patients treated at the hospital are referred to this outpatient clinic, called "Out of Therapy," five years after being discharged from the oncology service. To remain under follow-up at the outpatient clinic, adolescents must show no signs of disease recurrence. The five years is based on the literature, which considers this period an indicator of cure and survival(2,4,20,21).

Participants were recruited through the institution's daily appointment schedule. Adolescents were approached in the outpatient waiting room while waiting for their appointment, following the order of scheduling, provided they met the study inclusion criteria: age between 12 and 25 years, being a cancer survivor treated at the Out of Therapy outpatient clinic, and residing in the city of São Paulo or its metropolitan area. Data, including confirmation of diagnosis, treatment duration, and cure, were obtained from the patients' medical records.

One of the researchers introduced herself to the adolescents and their families, explained the research objectives, invited them to participate in the study, and assured them of anonymity, absolute confidentiality of information, and the freedom to participate or not. Participants were given the option of having the interview conducted right there in the clinic or at a later meeting at their home or another location of their choice.

Six of the interviews were conducted at the clinic, six were conducted at the participants' homes, one adolescent chose to be interviewed at the university where he studied, and one adolescent requested that the interview be conducted at a shopping mall. During the interviews, every effort was made to ensure the adolescents' greater privacy. The average duration of the interviews was 50 minutes, and questions about returning to school were used, according to the adolescents' age, to explore their perceptions of the phenomenon.

The semi-structured interviews were recorded and subsequently transcribed in full. The participating adolescents were designated with the letter "P", followed by a numerical sequence corresponding to the order of the interviews. Notes were taken immediately after the interviews to avoid loss or alteration of data.

The data analysis process was based on thematic analysis. This process is both interactive and reflective, allowing for the simultaneous collection and analysis of data. This approach enhances the interactivity of qualitative data analysis, contributing to the overall reliability and rigor of the research method(22). In this study, we opted for the hybrid model among the different approaches to thematic analysis. This model employs deductive reasoning from predetermined codes and an inductive approach based on data(18).

The entire analysis process was conducted by one researcher and subsequently reviewed by two other researchers. Divergent points were discussed and agreed upon. The thematic analysis process took place in six phases: familiarization with the data, which consisted of transcribing the data, reading and rereading the interview data; initial coding, comprising the creation of the first codes to be grouped systematically; search for patterns of related responses, grouping the codes into potential themes; review of themes, in which the relationship between the themes found, the data, and the initial coding was investigated, generating a thematic analysis map; definition and naming of the themes that comprised the organization of the collected data, according to the predefined themes; and description of the results, the final phase of the analysis, and the main conclusions found(18,22).

The study was approved by the Research Ethics Committee, as per Certificate of Ethical Review No. 68985317.3.0000.5392. A free and informed consent form was signed by each adolescent's guardian and the researcher. Another consent form was signed by the adolescent and the researcher, in accordance with the ethical guidelines for research involving human subjects(23).

Four themes were identified at a latent level, involving an interpretative task, in addition to the semantic content of the data: *not telling anyone about having cancer, suffering bullying at school, facing prejudice, and seeking normality*.

RESULTS

Fourteen adolescents aged 12 to 22 years participated in the study (Table 1). Diagnoses varied between: Acute lymphoid leukemia (ALL); Acute myeloid leukemia (AML); Neuroblastoma; Medulloblastoma; Langerhans cell histiocytosis; and Wilms tumor. The time between diagnosis and cure ranged from 5 months to 3 years. The time between diagnosis and the start of follow-up at the Out of Therapy outpatient clinic ranged from 5 to 9 years.

At the end of treatment, adolescents undergo an adjustment to their new reality, now bearing the marks, signs, and trauma caused by the disease and treatment. In most cancer treatments, child and adolescent patients stop attending school. This is due to recurring hospitalizations or even the effects of treatment. School life stands out among these necessary readjustments.

This new adaptation to school life brings with it some difficulties caused by prejudice, due to physical appearance or the stigma of the disease itself. To better adapt to their new reality, adolescents have developed some strategies.

Not telling anyone about having cancer

Opening up to others about their history is not an easy task

Table 1 - Characterization of adolescent cancer survivors (n=14), São Paulo, São Paulo, Brazil, 2019

P[A]	Age (in years)	Disease	Age at the start of treatment	Age at the end of treatment	Age at the start of follow-up at the out of therapy outpatient clinic	Year when follow-up at the out of therapy outpatient clinic started
P1	18	ALL[B]	6 years	8 years	13 years	2012
P2	17	ALL[B]	3 years and 8 months	5 years and 11 months	10 years	2010
P3	12	Neuroblastoma IV	1 year and 8 months	3 years and 8 months	8 years	2015
P4	12	Neuroblastoma IV	11 months	1 year and 4 months	6 years	2013
P5	12	Wilms tumor	1 year and 2 months	2 years and 9 months	7 years	2014
P6	12	Wilms tumor	2 years and 3 months	3 years and 11 months	8 years	2014
P7	18	Langerhans cell histiocytosis	5 years	6 years	11 years	2011
P8	16	Neuroblastoma IV	1 year and 7 months	3 years and 11 months	8 years	2011
P9	13	Medulloblastoma	3 years and 11 months	5 years and 1 mês	10 years	2014
P10	17	ALL[B]	2 years and 10 months	5 years	10 years	2011
P11	22	AML[C]	12 years	14 years	19 years	2014
P12	21	ALL[B]	3 years and 11 months	6 years and 5 months	11 years	2009
P13	22	ALL[B]	2 years and 9 months	4 years and 8 months	9 years	2006
P14	16	Non-Hodgkin lymphoma	3 years and 7 months	6 years and 2 months	12 years	2010

Note: [A]P: Patient; [B]ALL: Acute lymphoid leukemia; [C]AML: Acute myeloid leukemia.

for cancer survivors. Adolescents show discomfort in sharing their childhood cancer experience with their peers, and this is because they do not like to be seen as victims, looked at with pity, or treated differently because they experienced cancer in childhood.

> *I do not talk much about having had cancer. I do not think I have ever discussed it with anyone. I do not see the need to discuss what happened. (P9)*

> *However, I do not go around telling people either; it is not something you share with everyone that you have been sick. I do not like telling people. (P12)*

> *I am ashamed to talk about it; I do not like talking about my illness to others. (P5)*

> *I went to school wearing a cap because my hair was falling out. (P1)*

This need to hide the experience of cancer reveals itself as a protective strategy to avoid the judgment of others and continue to be seen as usual. The narratives indicate a concern with the opinion of others, who may perceive them as victims or hostages of a situation.

> *I do not like to talk about having had cancer (...) because many people look at you and say things like, "Oh, you poor thing." I hate that phrase: "You poor thing," "Oh, how sad!", "What a pity!", "Wow, you did not have a childhood." Yes, I did! I had a perfect childhood in the hospital. I played, I jumped. I could not (laughs), but I jumped. (P13)*

Adolescents also reveal that they feel tired of telling their story or giving explanations about everything they have been through during the course of their illness, and clarifying that they are cured. They reveal that they are questioned whenever someone notices their scars and that this situation makes them feel the need to hide the marks left by the disease.

> *People ask about my scar. Everyone keeps asking every day. You have to repeat, repeat, repeat. Then I have to talk and explain. Explain that I have been cured and everything. (P5)*

For adolescent cancer survivors, it becomes unbearable to be treated with pity or as if they were still sick. They want to leave the scars of the disease in the past and live like any other teenager.

Suffering bullying at school

The obstacles encountered when returning to school mainly relate to acceptance by peers, physical appearance, and difficulties in socializing in the school environment. The lack of empathy from peers and feelings of rejection encountered during this period of readjustment to school are highlighted in the adolescents' narratives.

> *At school, it is not like any other child, but we suffer a bit of bullying...they call me fat. I feel sad, but I ignore it and move on. (P3)*

> *...at school, the kids bother me, they make fun of me, they call me big head. I feel bad. I feel sad, and I walk away from them. However, when I am here (at the clinic), no one can bother me. (P14)*

> *Our hair falls out, and then it is hard to go to school. There is the acceptance of people, of you being around them, looking like that, different from everyday life, from what human beings are used to. (...) When my hair was falling out, there was rejection at school. Many friends talked about it, making fun of me and laughing at me. However, it is a phase we have to go through. (P5)*

Upon returning to school, adolescents face yet another challenge. School is yet another obstacle to overcome, an inhospitable environment, with room for bullying due to their physical appearance, resulting from the treatment.

Facing prejudice

For the adolescents, fighting prejudice is just as problematic as fighting the disease. They consider themselves survivors of the prejudice they have suffered, constantly stressed by malicious comments about the disease and people's lack of sensitivity toward their suffering.

> *I think I am more of a survivor, not because of the disease, but because of prejudice. Because of everything people said, behind my back or even to my face, "Oh, you should not be here." Those were really harsh things to say. However, I think I am more of a survivor because of that, because people do not know what another person's pain is like, rather than because of what I went through. (P11)*

> *She said, "Oh, there is no cure." I replied, "No! I am fine." (...) That stressed me out. That is when I spoke up, and I spoke very nervously. I wanted to cry out of hatred, because I wanted to punch her in the face: 'Just because one person did not survive does not mean that everyone else is doomed to die. It is not like that. I am alive. Other people have been through the same thing and are alive.' (P12)*

Adolescents reveal the difficulty in transitioning from the "world" of the hospital, where they feel safe, to a "new world" that they identify as strange, with people who do not know their stories or are not sensitive to them. The transition from the safety of hospital care to school life and living with strangers brings feelings of insecurity and helplessness.

> *It was harder for me to go to a world I did not know, with prejudice, and leave a world of care. I had much love for the nurses, physicians, my mother, and my family. I left for a world I did not*

> *know, a world of strangers, people who did not understand suffering, who did not understand why it persisted. That part was the hardest. People did not look at me with compassion! For me, that was the hardest part. (...) Inside the hospital, it was like heaven for me, and outside, it was like a place of monsters. I had no peace, you know? I tried, but some people always seemed to want to bring me down and make me sad. (P13)*

Cancer survivors attribute a new perspective to the care they received during treatment: safety. For them, the health service where they underwent treatment is a safe place, and healthcare professionals convey a sense of protection. Back at school, they need to learn to live with prejudice and isolation and protect themselves from comments lacking empathy.

Seeking normality

The adolescents reveal that, at the end of treatment, they want to live like other adolescents who have not had cancer, play sports, work, and study. They want to have an everyday life like any other young person their age, seeking to engage in activities appropriate for this stage of life.

In their new reality outside the hospital, adolescent cancer survivors seek to adapt to the routine of young people their age, seek normality, and want to live like any other teenager. They long for a life without worries about the disease, in which they can engage in activities that are accepted and valued by society.

> *I wanted to live like everyone else, without any illness, without any health concerns, without worrying that something might happen. Today I can. I study, I work [pause], I play sports, I play, I run, I jump. I do everything that anyone else does. The illness has not interfered with anything. (P10)*

> *My life is normal today. I am a normal girl, just like the others. Today, I am just like them. I do not see any difference. I am ordinary; I can do everything other girls do. They are smart, and so am I. There is nothing like having cancer for me; it did not change me at all. You know? It is as if I had nothing. If I do not tell anyone, no one knows. I am like a normal child, just like the others. (P6)*

> *Today, my life is completely normal. What we went through does not affect me at all. I remember very little. (P8)*

These young people show that they are no less capable than other teenagers because they have undergone cancer treatment, and that the process they have been through does not interfere with any of their abilities. However, despite their quest for normality, they emphasize that they are different people because of their experience with cancer, and they want to be recognized for that.

> *I believe that any illness, such as cancer, teaches us a valuable lesson. In one way or another, consciously or not, it ultimately affects us in some way; we become different, and we look at life or people differently. We end up with a different essence (...). All the children there are different, because we have all been through something serious - an illness. However, we share a commonality: we are the same in terms of how we will live our lives from now on. (P13)*

Cancer treatment has a significant influence on the identity formation of survivors. Adolescents experience ambiguous feelings; they do not want to be perceived as different from their peers, but they want to be recognized for their unique life trajectories.

DISCUSSION

The study contributes to expanding knowledge about returning to school after childhood cancer treatment, a topic that has been little explored in Brazil. Based on the evidence gathered in this study, we found that it is essential to support adolescents in reintegrating into school and that there is a need to coordinate actions among hospital services, primary care services, and schools.

At the end of treatment, survivors face a series of personal challenges, feeling physically tired, emotionally unstable, and socially disconnected. In addition, they face a lack of recognition of their suffering by others(24-26).

Talking about cancer is difficult for adolescents because they believe that revealing their condition will make others uncomfortable, hindering the process of interacting with their peers. They fear that revealing their survival will change the way others see them, being considered a “cancer patient” as opposed to a “normal classmate”(12).

Teenage cancer survivors need to learn to live with these differences after the end of treatment, as well as to attribute meaning to the things they have experienced(17). Erroneous beliefs still surround cancer that it is contagious, genetic, and spreads from generation to generation. It is also associated with punishment(25) or a death sentence(27), which still generates prejudice and disbelief in treatment.

Among the conditions faced at the end of cancer treatment, survivors may experience physical, mental, emotional, spiritual, social, educational, and employment problems(6,8,28). Adolescent cancer survivors may feel disconnected from their peers or insecure about their physical appearance, may feel that their cognitive and physical abilities are diminished, and that they have been “left behind” in relation to their peers(28).

An adolescent who has been cured of cancer may carry physical marks on their body from the threat that affected their life. This altered body image affects their return to social life and school, which can increase the occurrence of bullying(29).

Studies indicate that adolescent cancer survivors have problems related to socialization at school. They show that these young people suffer bullying due to their altered body image as a result of treatment and cure(29). Preventing bullying requires intersectoral efforts between schools and health services, through innovative and participatory educational approaches that encourage information sharing and foster bonds among these adolescents, their peers, teachers, and the entire school community(29,30).

Even survivors who show no physical changes avoid talking about cancer, as sharing their experience with others can lead to looks of pity and feelings of sympathy, or even changes in the way they are treated. Having a history of cancer carries a strong social stigma; for this reason, many people may not want to be labeled as survivors or considered "different"(31). It can be exhausting for survivors to share their life story with others repeatedly and continually recall what they have been through(32).

For adolescent cancer survivors, it becomes unbearable to be treated with pity or as if they were still sick. Like any other adolescent, they seek to be like their peers and belong to a group. Adolescents feel that participation in school involves more than just getting involved in activities; in fact, they seek a sense of belonging, keeping up with their healthy peers, and the ability to engage in social interactions(33). Interactions should take into account what each adolescent feels and understands as essential at that particular moment. Understanding oneself and others leads to better education, improved coping with difficulties, and a more effective way of carrying out one's own plans(17).

Social connection is a determinant of health that is associated with longer life expectancy, improved mental health, enhanced cognitive functioning, and better neuroendocrine and immune regulation(34). Human beings are social creatures, and social interaction for cancer patients is associated with improved social and emotional well-being, increased social support, and reduced mortality(17,34). Thus, social interaction, social support, and a sense of belonging can promote the well-being of adolescents going through the experience of cancer(33).

Social contexts play a crucial role in minimizing social isolation and fostering connections between people. Among these social contexts, school stands out as the primary space for socializing and forming bonds among young people(33). School is a vital environment for social interactions among teachers, students, family members, and healthcare professionals. It is also a space with potential for intersectoral coordination, such as creating bonds between health teams and the school community, monitoring the health conditions of schoolchildren, expanding access to health information, bringing families closer to the actions developed, and partnering with other sectors(35).

The Ministry of Education's School Health Program (acronym in Portuguese, PSE) has an intersectoral policy based on comprehensiveness, territoriality, and intersectorality, which aims to promote children's health and development by fostering partnerships between public schools and primary healthcare units(35).

The partnership between education and health professionals can help cancer survivors better adapt to school and social activities, thereby minimizing difficulties and frustrations with reintegration into school(35). Schools play a fundamental role in promoting a sense of normality and helping adolescents who are cancer survivors build their 'self' and sense of purpose(36).

The self is defined and redefined socially, as the definitions made by others serve as a reference for the person to see themselves(17). Thus, the social interactions established upon returning to school will influence the reframing of the self for these adolescents. For symbolic interactionism, the way an individual sees and defines themselves, as well as the judgment they make about themselves, is highly related to the social interactions they have experienced. In this case, the entire experience of a serious illness and brutal treatment influenced the way these survivors view themselves(17).

For successful school reintegration, teachers and other professionals involved in the teaching and learning process play a crucial role. However, they need to be well-informed and feel confident and comfortable interacting with an adolescent cancer survivor in their classroom.

Human life consists of a series of actions resulting from a person's interaction with others, characterized by the way events are faced and the mechanisms used to deal with them(17). Thus, schools should encourage a respectful attitude toward a young person's cancer experience, help classmates adopt supportive roles, and ensure that teachers and other staff are aware of the students' situation(33).

It is necessary to prepare these adolescents to return to their activities after the end of treatment(8). This preparation involves striking a balance in perception between what is considered normal and what is culturally acceptable to society.

The adolescent's return to school brings a sense of normality, a feeling of being similar to and belonging to the group, as well as the search for independence, providing a condition of expectation for a prosperous future without the disease(8). On the other hand, upon their return, they face complexity due to the search for recognition from peers and teachers(13,29). The narratives reveal a tension between wanting to be treated as if the cancer had never happened and the need for special consideration. Research in adult oncology supports this idea, indicating that resuming everyday activities can be challenging due to behavioral and health changes, which complicate the adjustment to a "new normal" following cancer(10).

Studies focusing on the care preferences of adolescent and young adult cancer survivors reveal their desire to feel "normal" and the focus of their survivor care on well-being rather than future risks(36,37). Parents of adolescent cancer survivors understand and describe their children's struggle to return to everyday life. They reveal that, despite fatigue and other symptoms, their children struggle daily to be more like their healthy peers(33,38).

The identity conflict between wanting to be treated as everyone else and, at the same time, seeking to be understood and recognized for having overcome cancer has been reported as a frequent conflict that permeates the lives of cancer survivors. Although they seek to build their identities without taking cancer into account, they also seek recognition for what they have been through. Young people do not like to be defined by cancer, but they affirm that cancer has made them who they are(27,38).

All the identified elements indicate that support programs should also include preparing parents(39) and identifying barriers and facilitators for cancer survivors returning to school. They need to be involved in this process.

The phenomena surrounding this group's return to school add new information to existing knowledge, considering the recently published umbrella review(40). Among the prospects for progress, the search for normality stands out.

Despite the study's contributions to understanding the perceptions of adolescent cancer survivors regarding their return to school, several limitations must be considered, including the data collection at only one cancer treatment reference health service, located in the capital city of São Paulo. Further studies should be conducted in other cities and regions of the country, addressing the experience of survival for adolescents treated at other reference centers outside the capital.

CONCLUSION

Understanding the challenges faced by adolescent cancer survivors when returning to school has revealed some of the strategies they use to strengthen themselves and overcome the obstacles posed by the complex school environment. These results can contribute to the planning of health professionals for the long-term follow-up of cancer survivors and include guidance on the difficulties that may be faced when returning to social activities, such as school.

Follow-up programs need to be developed in partnership with schools for childhood cancer survivors, with the aim of helping them adapt to school and minimizing the difficulties of inclusion for these adolescents.

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ECRG: validation; writing – original draft and writing – review & editing.

CAB: validation; writing – original draft and writing – review & editing.

RS: formal analysis; funding acquisition; investigation; methodology; project administration; resources; supervision; validation; visualization; writing – original draft and writing – review & editing.

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Conflict of Interest

None.

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