

## Explaining Palliative Care Needs for Families with Cancer Children (A Qualitative Study)

### Abstract

**Background:** Childhood malignancies give parents and children substantial psychological anguish and life disruption. One of the best strategies to enhance cancer patients' lives is palliative care. The present study aims to define the palliative care needs of families with children with cancer, identify strategies to address these needs, educate nursing staff to react as much as possible, and improve health care services. **Materials and Methods:** The current research was a qualitative investigation undertaken with the involvement of families of children diagnosed with cancer who were sent to educational hospitals in Ilam City in 2024. The data were collected via purposive sampling. Subsequently, data were gathered using semistructured interviews, and a guided content analysis was conducted for data analysis. The first stage of coding started by identifying the analysis unit, which encompasses words, phrases, topics, and sentences that possess distinct meanings. The primary ideas inside each analysis unit will be organized under the heading of the semantic unit. **Results:** This study included 10 individual interviews with diverse subjects. The interviews revealed four main categories and 12 subcategories of palliative care needs for families with children with cancer: psychological care (mental distress, homesickness, cancer taboo, and collapse of mental image), social care (lack of coherent support network, financial challenges, displacement, and out-of-hospital/telephone care), and physical care. Rethinking Spirituality was removed. **Conclusions:** Palliative care for children addresses medical, psychological, social, and spiritual issues to improve quality of life for the child and family. Correct and ethical treatment based on clinical recommendations is crucial.

**Keywords:** Cancer pain, child, nursing, palliative care, qualitative research

### Introduction

Childhood cancers that occur before the age of 18 are divided into a few malignant diseases, each of which has its own epidemiology and mortality rate. Malignancy is the most common cause of death in 1–16-year-olds.<sup>[1]</sup> Although the occurrence and spread of all types of cancer in people under 19 years of age are very rare and account for less than 1% of all cancers, they are considered one of the leading causes of death in children.<sup>[2]</sup> According to available statistics in Iran, between 1500 and 2000 children under the age of 15 receive a cancer diagnosis every year.<sup>[3]</sup> Iranian boys and girls report an incidence of childhood cancers of 112–48 and 141–51 per million people, respectively.<sup>[4]</sup> A cancer diagnosis can cause significant psychological stress for the person and their family. Cancer is important at any age, but its mortality is higher in children between the ages of 3

and 14 than in other diseases.<sup>[5]</sup> Due to their lack of knowledge about cancer, children do not feel fear, worry, despair, or depression. However, the parents' initial reaction plays a crucial role in transmitting and inducing negative emotions such as fear, anxiety, and sadness in the children. This, in turn, leads to the pain that arises after the progression of cancer or chemotherapy, most of which are psychological disorders. Children with chronic diseases, particularly cancer, often exhibit unique psychological and behavioral symptoms such as fatigue, psychomotor slowness, restlessness, muscle tension, nausea, digestive issues, hospital-induced anorexia or overeating, threshold issues, low pain tolerance, and sleep problems. Although cancer affects one person from a medical standpoint, family members share in the psychosocial problems of the disease. Caring for a child with cancer has a significant impact on parents. Parents of children with cancer have more severe

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depression symptoms and higher levels of post-traumatic stress symptoms, which harm family functioning and their quality of life.<sup>[6]</sup>

One of the most important issues and concerns related to children with cancer is paying attention to the quality of life and improving it. Palliative care is one of the most important and effective ways to improve the quality of life. Palliative care for children is unique due to the growth and development stages specific to each age period.<sup>[4]</sup> According to the World Health Organization report, only 14% of cancer patients receive palliative care. Caring for cancer patients includes all stages of the disease, from the time of cancer diagnosis to the end stages of life, and for this purpose, palliative care, which is comprehensive care of the patient and family, is emphasized.<sup>[7]</sup> There is solid and strong evidence confirming the positive effects of palliative care services in reducing disease burden, improving satisfaction, and increasing patients' quality of life.<sup>[8]</sup> Palliative care is patient- and family-oriented care that changes the quality of life during the disease and can ease the symptoms, discomfort, and stress in children with life-threatening diseases and their families.<sup>[9]</sup> Given the complexity of cancer treatment and its complications, the patient and their family require comprehensive palliative care. Cancer patients and their caregivers frequently do not have correct information about the disease's diagnosis, prognosis, and complications; how to adapt to the conditions; and how to receive support system services. Considering the importance and necessity of providing palliative care services, a system for training in the management of symptoms and how to treat and cope with the disease seems essential for patients and their families.<sup>[10]</sup> In addition, palliative care obstacles are placed in several categories, which include the high workload of nurses, death anxiety, lack of sufficient training, lack of communication between the nursing team and the doctor in the field of caring for family members, being out of the scope of nursing practice, the unwillingness of nurses to communicate with family members of dying patients, unrealistic expectations of treatment, and lack of communication. Patients and their families have the right to receive palliative care at the end of life, but most nurses lack the necessary preparation to provide this type of care.<sup>[11]</sup> Despite palliative care's complexity and multifaceted nature, our country's educational program fails to adequately explain and seriously consider the existing knowledge in this field. The lack of qualitative studies on palliative care has limited its use in research.<sup>[12]</sup>

Teaching palliative care to nurses is considered essential because spending more time and more work and mental conflicts with these patients and their families plays a critical role in caring for them, changing their experience of death, and improving their quality of life. This new concept in nursing encompasses the prevention, examination, and treatment of physical and mental issues in patients with

incurable diseases.<sup>[12]</sup> Therefore, the current research was conducted to explain the palliative care needs of families with children with cancer, to predict ways to meet these needs, and to train the nursing staff to respond as much as possible to these patient needs and to increase the quality of the health care services provided.

## Materials and Methods

The present qualitative research was conducted using a directed content analysis method, which allowed us to systematically code and categorize participants' experiences based on both predefined concepts and emerging data, that began in July 2023 and ended in January 2024. Data were collected through semistructured interviews using open-ended questions. Before conducting each interview, the researcher, present in the research environment, introduces himself, explains the nature and main purpose of the research, identifies the appropriate participant, and obtains written consent specifying its contents. The parties then agree on an appropriate time and place based on their preferences. The participant's preference is determined. In the present study, in the shortest possible time after conducting the interview, the entire text was carefully read until a deep and correct understanding of it was obtained; then, those parts of the text that were determined based on the researcher's initial impression were marked and became the smallest meaningful units (code). In the next step, the marked parts were coded.

To achieve this, the text of the files was first listened to several times, then entered into the word software, and then carefully read several times, with key phrases and sentences underlined. Then, the codes (the main meanings of the participants) were extracted. The first-level coding process started with identifying the units of analysis, that is, words, phrases, themes, and sentences with special meanings. Then, the main concepts in each analysis unit were placed under the title of the semantic unit. After completing 10 interviews, 645 initial codes were extracted at this stage. At this stage, by reviewing the manuscripts again, the researcher categorized the similar codes into separate categories and determined subcategories for each category; thus, initially, 106 subcategories (the initial concept) were extracted, and after analysis and continuous comparison of categories and codes, 12 subcategories and 4 categories were obtained.

The data's trustworthiness was evaluated based on the standards established by Lincoln and Guba.<sup>[13]</sup> The requirements include credibility, confirmability, reliability, and transferability. This research included a thorough and extensive process of collecting and analyzing data. The data were also reviewed by supervisors and consultants before being used. In addition, the results were thoroughly analyzed by an objective observer. To ensure confirmability, meticulous documentation of all study phases, particularly the comprehensive recording of data analysis in all aspects, was

undertaken. This facilitates easy comprehension for any future researcher wishing to pursue more research on this subject. The study methodology and participant characteristics were thoroughly elucidated to enable an accurate assessment of the transferability of the findings to other readers.

**Ethical considerations**

This work is a product of research that has received approval from the ethics committee of Ilam University of Medical Sciences with the reference number IR.MEDILAM.REC.1401.144. Interviews and audio recordings were done subsequent to participants’ comprehension of the study’s objective and provision of informed consent. Participants were informed that the recorded information would be kept anonymous, and they were notified that they had the option to withdraw from the research at any time “without any consequences”.

**Results**

In this study, the perception of families of children with leukemia about the care needs of children with leukemia was explained through guided content analysis. Ten interviews were conducted individually with a wide range of participants with different characteristics, whose characteristics are listed in Table 1 by family caregivers.

Table 1 shows that most of the participants in the research were mothers of children; the level of education of most of them was a diploma, and they were housewives. Table 2 shows the main care needs and challenges of not caring for children with cancer. Below, some interviews with the patients’ caregivers have been explained and presented.

**Category 1: Need for mental health care**

Psychological care takes into consideration the wellbeing of the child and the family. It considers the effects of the disease on the behavioral, cognitive, and emotional states, the personality of each family member, coping methods, and past experiences. This category includes the subcategories of mental distress, homesickness, cancer taboo, and collapse of mental image.

*Mental distress*

According to the participants, having a child with cancer is stressful, and the child and the family experience the most difficult period of their lives due to being involved in the process of the disease and treatment and situations such as depression, reduced resistance to problems, and imbalance in life. *“For some mothers, when they hear the news of their child’s illness, their spirits are very broken. I have seen many mothers react in distress, pulling their hair and beating themselves when they hear such news.”*

*Homesickness*

The findings of the research showed that children stay away from family members and friends during hospitalization

**Table 1: Demographic characteristics of family caregivers of children with cancer**

Age	Education	Relation to Child	Occupation	Interview time (minute)
40	Diploma	Mother	Housewife	26
56	Diploma	Father	Worker	36
13	Secondary School	Sister	Student	18
34	Diploma	Mother	Housewife	32
38	Diploma	Aunt	Housewife	15
35	Illiterate	Mother	Housewife	11
32	High School	Mother	Housewife	25
36	Diploma	Mother	Housewife	22
29	Diploma	Mother	Housewife	110
32	Bachelor of Art	Mother	Housewife	63

**Table 2: Category and subcategories for children with cancer**

Category	Subcategory
Need for Mental Health Care	Mental distress
	Homesickness
	Cancer taboo
	Collapse of mental image
Need for Social Care	Lack of coherent support network
	Financial challenges
	Displacement
Need for Physical Care	Out-of-hospital/telephone care
	Inadequate pain management
Need for Spiritual Care	Alternative therapy
	Seeking spiritual peace
	Rethinking spiritual beliefs

and due to treatment procedures, and they show symptoms such as fatigue, isolation, and boredom, which can be due to being away from family and homesickness. *“Every day, when he was hospitalized, he called me every day, saying, when are they going to let me come? He missed us a lot, and he said, “I miss you a lot when it gets dark. (Sister of a 6-year-old child).”*

*“He went to the third grade, but last year, I didn’t let him go. Well, he can’t. He doesn’t feel like studying at all. How can I send him away? When he says he doesn’t want to, he can’t write much. So, what should I do? I want him to go, but he doesn’t like it. (Mother of a 10-year-old child)”.*

*Cancer taboo*

The participants believed that the people around them and the people in society have a wrong and negative view of the child’s illness, which causes the family to disconnect from the people around them and their culture, and the family does not share their problems with anyone. These events increase the burden of disease problems on the family. *“For example, Mr... was our friend; he was not even present; he refused all his invitations, for example... he would tell him, I want*

to come, and he would say, No, no, no... No, for example, I will invite you to such and such a place. Weddings, funerals, social contact cut off. (Father of a 10-year-old child)."

"I saw with my own eyes that whatever it is, they look very bad, very bad, so that, for example, if the other two people don't notice something like this immediately with this look, with this behavior...or, for example, come this way, come that way, they feel that this disease is contagious, or they don't know the name of this disease, what is it, don't say anymore. (Mother of an 8-year-old child)."

### **Collapse of mental image**

According to the participants, losing a child's hair hurts the child and the family, and it changes society's view of the child. Alopecia isolates most children, leading to a change in their self-image. During this period, some children, especially girls, are intensely interested in hairdos, make-up, and bright clothes. "And then they always like to buy clothes. I don't know why. My daughter is like this. My daughter is like this. They have another friend who is like this. One of them is also like this. They always like to wear beautiful clothes. For example, my daughter likes me a lot. It's crucial for her. She says no; when we go out, you have to make up. She wants to see me like that. (Mother of a 10-year-old child)."

"My daughter had yellow hair up to this point. The day I came here, I saw everything like this. The doctor told her to wear a scarf. Following the initiation of chemotherapy, her hair began to fall out at a rapid pace. (Mother of an 8-year-old child)."

### **Category 2: Need for social care**

One of the important pillars of holistic care is social support. It should be done based on understanding the position of the family and the child in the family network, friends and society, interactions, and communications. This category includes subcategories of lack of a coherent support network, financial challenges, displacement, and out-of-hospital/telephone care.

#### **Lack of a coherent support network**

The findings of the research showed that having good relationships and support resources from the surrounding people and the family is one of the factors that reduce the burden of the disease on the child and the family, and the absence of these positive factors has a negative effect on the child and the family. "They are very good; for example, my brother-in-law, my brother-in-law, my mother, and everyone is taking care of that one, my children. They tell me to take care of yourself; go to this one, baby; they won't be harmed; you reach out to this one who is sick; they will get well; they themselves will be fine. We take care of them. (Mother of a 5-year-old child)."

"No matter what happens, I won't tell anyone. I try to make sure that I don't tell anyone. What can they do to me besides the inconvenience it causes the family? No, I won't

tell anyone. Besides, if I want to tell anyone, that's it." My friends are here. They can't do anything for me. (Mother of a 10-year-old child)."

#### **Financial challenges**

According to the opinions of the participants, most of the families with sick children do not have a good financial situation, and the help of charities is not enough. "We don't have a house for ourselves at all. The work is free. The work goes to the brick factory, which is there. He gets the bricks and sells them. It depends; for example, he might sell his bricks in one day, but maybe he stays for a week and no one comes to buy them. That's why sometimes it's good. Sometimes, not a lot. We couldn't do it if it wasn't a benchmark. (Mother of a 10-year-old child)."

"Because of the financial and emotional needs, I was very broken. His father is unemployed. He is the same specialist who owns the institute. His advice helped me a lot. A lot. I told him how much his help meant to me, and he provided significant assistance. He gave me rent money. He gave me 1 million toman; he has helped me so far. 60 tomans. I told him everything. Doctor, I can't run, and come and help me. (Mother of a 12-year-old child)."

#### **Displacement**

Most of the hospitalized patients came from the cities, and their families had nowhere to stay. Many of these families lost their jobs due to distance from home, disrupting their daily lives. "It is the only thing that is observed everywhere, but Khuzestan, a big metropolitan city like Ahvaz, is not observed. They just put the adjacent rooms in the same way, but although they take a lot of patients, they make the rooms 5 beds, 6 beds, etc. It means that I, along with my mother, should go find a corner for myself or come down from these two beds so that neither she nor my child gets hurt. (Mother of a 5-year-old child)."

#### **Out-of-hospital/telephone care**

Many participants were willing to solve some of the complications caused by their child at home over the phone rather than travel a long distance to the treatment city. "I called the doctor and informed him about the current situation; he advised me to refer him to a specialist, for instance." Because he was a general doctor, had no information about this disease. Talk to the doctor. He said that he would prescribe this medicine... there was no need for me to bring him to Ahvaz. (Child's father)."

### **Category 3: Need for physical care**

Managing the symptoms of the disease, including physical symptoms and pain, is to achieve the wellbeing of the child and the family and reduce pain comprehensively and holistically. This category encompasses the subcategories of inadequate pain management and alternative therapy.

#### **Inadequate pain management**

According to the study's findings, children endure a lot of

pain during hospitalization following invasive procedures and treatment, and the only way to reduce pain and support them is to use drug therapy. *“Many children are so bothered by the closed-mouthed child; for example, Mehdi told the first person that you treat us like sheep. (Father of a 10-year-old child).”*

*“Yes, he was in a lot of pain; he was crying; even sometimes I cry with him; he is in a lot of pain, yes. (Sister of a 6-year-old child).”*

#### *Alternative therapy*

According to the opinions of the participants, the fun and joyful facilities for children are very limited, while the existence of such facilities is very effective in improving their mood. *“For example, the boys were very happy yesterday, not because we gave them a car. The girls weren't upset, and we didn't give them anything. We didn't give them dolls, but they like cars. But it has a very, very great effect. You might not believe that we used to come in the corridor; everyone was playing outside and having fun. That's why I say it affects their mood a lot. (Mother of a 10-year-old child).”*

#### **Category 4: Need for spiritual care**

According to research participants, spiritual care supports a sense of hope, value, purpose, connection with others, and connection to a greater power in the child and family. As a part of holistic care, the participants found spiritual support to be comforting, but some were confused about this.

#### *Seeking spiritual peace*

Some participants believed that the remembrance of God and religious practices can heal and reduce the child's pain and illness, but proper support is not provided in this regard. *“I hadn't slept for two nights. The creature's noise disturbed even my bed, and it was painful, not that she cried all the time. Then it was almost morning, and I prayed. I said, God, you say you are more compassionate than my mother; so why? Look, so how do you feel? God, you may not believe that since I prayed this prayer, this 5-year-old creature has not felt these pains at all. (Mother of a 10-year-old child).”*

*“I didn't see any facilities or religious ceremonies. They don't even have a prayer room; there is a small room for everyone. I spread my tent and prayed on the floor. (Mother of a 5-year-old child).”*

#### *Rethinking spiritual beliefs*

According to the findings of the study, some participants have weakened their beliefs after a while, so the need for a religious and spiritual supporter and advisor is evident. *“Nothing; we simply offer our primary prayers.” You may not believe that I used to pray a lot while fasting, but not now, as if we were tired. We are forcing ourselves to pray. This is how it is... I think this is how it is. Now I*

*understand why, but some of them are just like me. In other words, while they pray, not all of them experience fatigue.”*

## **Discussion**

A child with cancer and his family experiences many problems in different dimensions of their personal, family, and social lives. In order to prevent the negative consequences of the disease and improve the quality of life, there is a need for a comprehensive and extensive system of supportive and palliative care. It is felt. The present study was conducted with the general aim of explaining the palliative care needs of families with children with cancer. The participants in this research believed that children with cancer need care in psychological, social, physical, and spiritual areas to increase their quality of life. Psychological care considers the child's and family's wellbeing, as well as the effects of the disease on the behavioral, cognitive, and emotional states; the personality of each family member; coping methods; and past experiences. This category includes the subcategories of mental distress, homesickness, cancer taboo, and mental image collapse. Psychological distress is a subcategory of the need for psychological care. The findings of the research revealed that children avoid their family and friends during hospitalization and treatment procedures, exhibiting symptoms such as fatigue, depression, isolation, and boredom. A study by Pangarso *et al.*<sup>[14]</sup> showed that the average depression in the cancer-affected group was significantly higher than that in the healthy group. This study explained that chronic and life-threatening diseases in children and adolescents intensify the challenges that exist in the context of the basic tasks of child and adolescent development.<sup>[15]</sup> These challenges encompass issues such as autonomy, relationships with peers, and future orientation, while also involving factors related to the patient's role and sometimes treatments that may distance the child or teenager from society.<sup>[2]</sup> Another subcategory was the cancer taboo. A taboo is a culture or custom that prevents people from doing, using, or talking about a certain thing because it is considered shameful or offensive.<sup>[4]</sup> Studies have shown that cancer is taboo in Spain and Asian countries.<sup>[16]</sup> According to the participants' statements, cancer is considered taboo in Iran.<sup>[17]</sup> Darby and his colleagues also view education as a logical solution to dispel the taboo surrounding cancer, and they advocate for the use of media, volunteers, and similar resources to promote awareness of the disease in society, as pointed out.<sup>[18]</sup> Education can correct beliefs by changing people's attitudes, preparing society as an important source of support in accepting children and families, and providing them with the means of a normal life.<sup>[19]</sup> Children with cancer usually have problems related to their mental image. For example, a child's sudden hair loss after chemotherapy causes him to be distinguished from others and ridiculed by his peers. In the present

study, mental image problems in children, especially girls, have been mentioned. Chong *et al.*'s study has pointed to the collapse of children's self-image.<sup>[19]</sup> According to the results of this study, changes in physical conditions, lifestyle, and going to school can damage a child's personal and social identity.<sup>[15]</sup> Therefore, nurses and other caregivers must develop strategies for managing personal relationships and teaching communication skills to safeguard children's personal identity.

Social care is a crucial aspect of meeting the needs of families of children with cancer, and it involves comprehending the family's and the child's place within the family network, friends, and society, as well as their interactions and communications. This category includes lack of a coherent support network, financial challenges, displacement, and out-of-hospital or telephone care. The research findings indicate that having positive relationships and support resources from the surrounding community and family can significantly reduce the disease burden on the child and family. Conversely, the absence of these positive factors can have a negative impact on the child and family. In a study, the satisfaction and uniqueness of the role of volunteers in care, from the perspective of the patient and the family, are mentioned, which can be matched with the prevailing conditions, considering the cultural and religious background of the country and the existence of numerous charity associations. He knew about the country.<sup>[20]</sup> In Hammer *et al.*'s study,<sup>[15]</sup> families believed that they were under financial stress following the child's illness. Mothers had to take time off work to care for their children, so their income was reduced. In most countries, financial resources are provided through government and charity.<sup>[5]</sup> Other issues faced by the participants included the absence of healthcare facilities in their home areas and the transfer from urban areas to healthcare facilities, a phenomenon known as displacement. Many of these families had lost their jobs due to being far away from their place of residence, and their daily routine was disrupted. Various studies have shown that the higher the amount of social support, the higher the probability of recovery and the use of coping methods.<sup>[21]</sup> The research has also revealed the need for physical care. Managing the symptoms of the disease, including physical symptoms and pain, is to achieve the wellbeing of the child and the family and reduce pain comprehensively and holistically. This category encompasses the subcategories of inadequate pain management and alternative therapy. Children suffer a lot of pain during hospitalization following invasive procedures and treatment, and the only way to reduce their pain and support them is to use drug therapy, according to the study's findings. In Iran, available drugs for pain control are not used in an organized way, so all kinds of inappropriate use are widely seen. Standard clinical guidelines issued by academic committees in collaboration with the Ministry of Health may help resolve these issues. As a result, inadequate pain management is

one of the biggest concerns for Middle Eastern countries.<sup>[8]</sup> According to the participants, children have limited access to fun and joyful facilities and games, although these facilities can significantly boost their morale. It is referred to as alternative therapy. Another well-known requirement is spiritual care.

Spiritual care promotes a sense of hope, value, purpose, connection with others, and connection to a greater power within the child and family. This category was identified with two subcategories: "Seeking Spiritual Peace" and "Rethinking Spiritual Beliefs". Spirituality is a complex concept that is defined and measured in nursing literature.<sup>[22]</sup> Some participants believed that the remembrance of God and religious practices would heal and reduce the child's pain and illness, but the proper place and support were not provided in this regard. Spiritual care seems necessary for parents during their child's illness as it appears they seek help from religion. Ebadinejad *et al.*<sup>[10]</sup> also recommended the use of spiritual and religious approaches as an effective solution for facing the tensions caused by cancer in Iranian society. Otth M *et al.* listed spiritual needs as one of the most important needs of patients with cancer and theirs,<sup>[23]</sup> and in line with this, the results of a qualitative study revealed that religion is the main component of a supportive factor to adapt to childhood cancer.<sup>[24]</sup>

This research possesses numerous advantages. This study addresses a critical deficiency in pediatric palliative care by examining the diverse requirements of families with children afflicted by cancer within a culturally appropriate framework. The application of directed content analysis facilitated both theory-informed and participant-driven insights, so augmenting the study's depth and relevance. In addition, the diversity of participants increased the transferability of the findings. However, the study also had limitations. It was conducted in a single geographic region, which may limit generalizability to broader populations. The small sample size, although suitable for qualitative research, might not capture all possible care needs. Furthermore, participants were recruited from hospital settings only, potentially overlooking perspectives of those who receive home-based or informal care.

## Conclusion

Noncommunicable diseases, including cancer, have emerged as the world's leading development challenge, and by assigning the highest death rate to themselves, they have impacted the world's development and economic progress. Children's cancer accounts for less than 1% of all types of cancer, and its prevalence is 50 to 200 out of every 1 million people in the world. About 80 to 85% of the cases occur in developing and less developed countries, with falls. Even though 80% of childhood cancers are successfully treated in developed countries, this rate is only 20% in developing countries. This discrepancy can

be attributed to factors such as late diagnosis, limited access to healthcare facilities, limited financial resources, population growth, and poverty. In situations where there is no treatment, the need for palliative care for children seems essential. By providing correct and standard care for a child with cancer, the opportunity for growth and development of the child, which is his right, is provided. Palliative care for children responds to physical, psychological, social, and spiritual needs to improve the quality of life for the child and the family. This is why providing correct primary care based on clinical guidelines is very important.

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### Conflicts of interest

Nothing to declare.

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