Diverse pathways to care for children with stomach pain in a Canadian cosmopolitan city

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Abstract
In Montreal, Quebec, 31% of the population is born outside Canada. Yet, only 9% of patient consultations for symptoms associated with functional gastrointestinal disorders (FGIDs) are from immigrants at the Paediatric Gastroenterology Clinic at Sainte-Justine’s University Hospital Centre. This discrepancy inspired a multidisciplinary exploratory study (anthropological and paediatric) to examine the sociological, interpretative and pragmatic aspects of immigrant and non-immigrant patients and family life with FGIDs. This paper examines the discrepancy between immigrant and non-immigrant paediatric patients with FGIDs and presents the different pathways to care utilised by families. Semi-structured interviews were carried out between November 2008 and June 2009, with children and their parents. In total, 38 families were recruited: with 27 families (including a child experiencing abdominal pain, his/her siblings, mother and/or father as well as any other significant individual living in the family home) from the community and 11 from the paediatric gastroenterology clinic. A comparative analysis between the immigrant and non-immigrant groups focused on perceptions, meanings and actions taken to relieve/alleviate symptoms. Immigrant and non-immigrant families alternate and combine different therapeutic environments: home, alternative healing therapies and medical paths to care. Our analysis suggests that culture (as a set of values, beliefs and ways of being), as well as social interactions within family life and the clinic, shape pathways to care. The analysis highlights the centrality of receptiveness – and more widely the social dimensions – of all medical encounters. Treatment disparities between immigrant and non-immigrant families in pathways to care help us to understand these patients’ social world and the intricate relationships between values and social milieux, between culture, practices of symptom management and rationales guiding diverse therapeutic actions.

Keywords: anthropology, childcare, clinical encounter, culture, functional gastrointestinal disorders, narratives, receptiveness

Introduction
Montreal is an urban cosmopolitan city that welcomes each year 30,000 to 40,000 immigrants from more than 100 different countries (Piche 2003, Gouvernement du Québec 2013). Although 31% of the city’s population is born outside Canada (Statistics Canada 2007), only a small percentage of immigrant families (9%) seek help for functional gastrointestinal disorders, very few immigrant families seek help from a gastroenterology paediatric clinic in a cosmopolitan urban centre.

What is known about this topic
- While 10% of children of all ages worldwide suffer from functional gastrointestinal disorders (FGIDs), very few immigrant families seek help from a gastroenterology paediatric clinic in a cosmopolitan urban centre.
- Differences in the proportion of immigrants and non-immigrants in the clinic population that could be explained by the different uses of health services and diagnostic methods.

What this paper adds
- Culture, as well as social interactions and relational dynamics within the family unit and medical encounter, shapes the illness trajectory and pathways to care in FGIDs.
- Receptiveness to children’s complaints of FGIDs, both within the family unit and during clinical encounters is a key feature in the illness trajectory.
- Non-immigrant parents and their children suffering from FGIDs more readily express a need for diagnostic and therapeutic certainty.

Non-immigrant parents and their children suffering from FGIDs more readily express a need for diagnostic and therapeutic certainty.
Introduction

Functional gastrointestinal disorders (FGIDs) and related symptoms at a tertiary paediatric gastroenterology hospital clinic (Caplan et al. 2005). Considering that the global prevalence is the same for immigrant and non-immigrant families (worldwide 10% of all children suffer from these medically unexplained disorders; Ramchandani et al. 2007, Birtwhistle 2009, Quigley et al. 2009), why then do so few immigrant families visiting paediatric clinics? International research in FGIDs (Statistics Canada 1999, Singh Setia et al. 2010) suggests that there is no significant difference in accessing healthcare between immigrant and non-immigrant families. Therefore, what do immigrant children and their families do when they experience FGIDs? Do immigrant families adopt alternative strategies to care for FGIDs that may explain their under-representation within the overall paediatric gastrointestinal disorders patient population? Do immigrant families view a child’s stomach pain as commonplace and therefore not requiring medical attention? Do immigrant children complain less frequently or do families’ immigration and resettlement preoccupations override these complaints and explain their under-representation in the gastroenterology clinic? These questions are central concerns of the collaborating paediatric team members and practitioners and guided our multidisciplinary study (anthropological and paediatric) that addressed the semiological, interpretative and pragmatic aspects of patient and family life with FGIDs. Specifically, this paper focuses on the discrepancy between immigrant and non-immigrant paediatric patient populations with regard to FGIDs and exposes the different paths to care that both immigrant and non-immigrant families undertake in response to their child’s symptoms. First, we will describe our research methods and findings. We will highlight the different therapeutic environments favoured by participating families: whether primarily emerging at the home, incorporating alternative healing therapies and entrance into the public healthcare system. We conclude by expanding upon the central issues in our analysis, summarising our contribution to the scientific literature and propose future avenues for research in FGIDs.

Pathways to care for FGIDs: when and why do families seek help?

Functional gastrointestinal disorders are recurrent gastrointestinal dysfunctions with no apparent physiological lesions, organ deficiency or pathological findings of the digestive tract. They are often referred to as stomach aches, abdominal pain, stomach gas or heart burn. With regard to the medically unexplained symptoms domain, there is still much unknown about the factors involved in the onset and evolution of FGIDs (Walker & Jones 2005, Rosh 2010). Nevertheless, there is an emerging consensus that a biopsychosocial approach to FGIDs may prove to be fruitful in understanding the illness-related phenomena at the biological, psychological and social levels (Fortin et al. 2012). However, the cultural factors related to the evolution of FGIDs have received little attention and remain unclear in the scientific literature (Howell et al. 2004, Kang 2005, Chang et al. 2006). From an anthropological perspective, FGIDs are not solely confined to the abdominal region. They embrace personal experience, life trajectories and social relationships in diverse settings, including the clinical space and broader healthcare environments beyond the material body. In turn, these dimensions colour the interpretation of FDIG symptoms, their meanings and the actions undertaken to alleviate suffering that give way to an array of healthcare pathways.

The current literature on the dynamics of healthcare-seeking behaviours of children with FGIDs offers a complementary, and yet partly contradictory findings. In the United States, a study of 507 adolescent students showed that medical consultations vary with the severity, frequency, duration and repercussions of the disorder on children’s everyday activities (Hyams et al. 1996). In this study, only 8% of the participants mentioned having seen a doctor for abdominal pain in the past year. Hyams et al. (1996) did not examine the correlation between family structure, ethnic background and decisions regarding seeking medical attention. For Koloski et al. (2003), the key factors for seeking medical advice are the persistence of the gastrointestinal disorder and the psychological distress of the child. However, other studies show that the decision to seek or not to seek medical attention is unrelated to the nature and intensity of the child’s symptoms according to biomedical criteria such as intensity of pain or frequency of symptoms (Venepalli et al. 2006, Lane et al. 2009). Rather, a mother’s perception plays a central role in seeking medical attention. If she believes that her child displays psychological distress (Levy et al. 2004), perceives that her child’s symptoms are severe (Lane et al. 2009) or that the stomach aches will persist and disrupt her child’s everyday activities (Venepalli et al. 2006), then a mother will probably seek medical advice. On the other hand, those mothers who consider their child’s stomach aches as normal or believe that the symptoms will disappear may not seek medical attention (Venepalli et al. 2006). According to these studies, there is also little difference between the symptoms of children who meet with a general practitioner (GP), a gastroin-
testinal specialist and for those who do not seek medi-
cal attention at all.

Furthermore, several reports mention the impor-
tance of parallel treatment with complementary alter-
native medicine (CAM) for FGIDs. Some treatments
(e.g. peppermint oil, hypnosis) are prescribed in bio-
medical settings, while CAM therapies (such as acu-
puncture) are sought after through alternative medicinal networks (Whitpuncture) or family networks (Schantz et al. 2003). Chavez (2003) shows that immigrant pop-
ulations in the United States often use medicinal
herbs, teas and infusions for minor health problems,
such as stomach aches and headaches. Chavez (2003)
also identifies specific socioeconomic factors that may
predispose certain families to turn to alternative ther-
apiies, including working long hours, thereby reducing
parental availability; linguistic barriers that restrict
access to certain healthcare services; and lower family
incomes, which limit access to transportation for
health services. On the other hand, Benoist (1996) and
Cathébras (1996) suggest that families turn to comple-
mentary and alternative healing strategies for prag-
matic reasons – to assuage painful symptoms and
improve overall well-being. This echoes Bluebond-
Langner et al.’s (2007) work on parental decision-
making in paediatric cancer. All avenues for treatment
and care are worthy of pursuit if they offer an oppor-
tunity to prolong the life and well-being of their child.

Family dynamics should be taken into consider-
ation to better understand families’ pathways to care
(Bluebond-Langner 1996) irrespective of whether care
is provided in the biomedical or family domain.
These dynamics may aggravate children’s symptoms and
influence how the latter are described (Janzen 1995). The perceived intensity of symptoms is stron-
ger in families that are more likely to attribute the
symptoms to a biological cause as well as with fami-
lies that experience conflictual relationships. In turn,
conflictual familial relationships are associated with
more severe gastrointestinal symptoms, while sup-
portive familial relationships are associated with less
severe symptom manifestation. The same trends have
been documented in the United States, Mexico,
Canada, England, Italy, Israel, India and China,
where there are more similarities than differences
despite the diverse national contexts (Gerson et al.
2006). According to Sullivan et al. (2001), there is a
positive correlation between the persistence of abdomin
pain and a tendency for exaggeration, irre-
spective of age, sex and the severity of symptoms.
They also suggest that patients may exaggerate their
pain to elicit empathy from those close to them and
to share their personal distress.

In her study of child healthcare among Caribbean
women in the United States, Yearwood (2007) points
out that the quality of a family’s past biomedical
encounters may also have a bearing on the child or
family’s pathways to care. In multicultural contexts,
differences in interpretation and narrative practices
can result in communication difficulties within clinical
encounters (Crushell et al. 2003, Fortin 2008,
Gauthier et al. 2008), leading to inequalities in the
evaluation of the condition and treatments offered
(Crowley-Matoka et al. 2009). Furthermore, biomedi-
cal culture impacts the entire clinical process, includ-
ing the expression, evaluation and management of
pain. Biomedical culture prioritises (i) the observable
in the mind–body dualism (Kleinman 1995, Lock
2002); (ii) the physical aspects of an illness experience
over the non-physical aspects; and (iii) biomedical
treatments over an overall well-being (Crowley-
Matoka et al. 2009). As a result of these priorities,
FGIDs are somewhat of a challenge for this biomi-
cultural disease model.

Nevertheless, Fassin (1992) reminds us that the
pathways to care, therapeutic itineraries and choices
can resonate with multiple rationales that stem from
structural issues (healthcare systems, medical tradi-
tions and social status) and other circumstances
(financial issues, social networks and familial con-
texts). Similarly, Scheper-Hughes and Lock (1987) as
well as Kleinman and Seeman (2000) remark upon
the reciprocal relationship between a patient’s social
world and the self, between illness experiences and
explanatory models, collective cultural values,
employment, the social milieu and macrosocial con-
texts. From this perspective, culture is understood as
a set of learned values, beliefs and ways of being,
which cannot be grasped exterior to social relations
that give them their meaning (Cuche 2001). Culture is
always ‘in the making’, and informs our understand-
ing of the world and social interactions – whose com-
ponents fluctuate and are engaged differently
according to the issues at hand (Clifford 1988,
Hannerz 1996).

One of the objectives in our study was to repre-
sent children and their families’ voices, hoping to bet-
ter understand their individual and collective
experience with FGIDs, and how this knowledge may
shed light on the different pathways to care at the
home, in the public healthcare system and comple-
mentary and alternative health therapies. We sought
to capture the different dimensions of FGIDs as a dis-
ease, an illness and a sickness throughout the course
of this study. Disease is a medically defined pathol-
ogy, while an illness represents the subjective experi-
ence, and sickness is the social phenomenon, which
become intertwined within our anthropological approach (Kleinman 1988). These distinctions are also intricately woven into the pathways to care. Parallel with Benoist (1996), Janzen (1995) as well as Fassin (2000), our aim was to further this understanding, incorporating culture and address how health and illness interact with social, contextual and perhaps the political aspects of care itineraries.

Methods

To understand the differences in the pathways to care between immigrant and non-immigrant families, we undertook an explorative qualitative study, interviewing 38 Montreal families with immigrant and non-immigrant backgrounds. By the term family, we include a child experiencing abdominal pain, his/her siblings, parents (mother and or father) as well as any other significant person living within the family home. We specifically recruited immigrant families in the light of their low visibility in the gastroenterology clinic at a tertiary free-standing paediatric research hospital in an urban cosmopolitan city. We interviewed parents (mother and or father) as well as children, conducting family interviews followed by one-to-one interviews with the child experiencing FGIDs.

Nine families were recruited in the gastroenterology clinic and 29 families from the local community. Recruiting families in the clinic followed a standard protocol for hospital settings. Families were informed of the study by their attending physician or clinic nurse, who gave the family an information sheet and invited them to contact the study co-ordinator; or if they preferred, families gave permission for the co-ordinator to contact them directly. As for the recruitment in the community, we posted an information flyer at local immigrant community associations, places of worship, primary and secondary schools and in neighbourhood newspapers. We accessed schools in specific neighbourhoods with larger rates of immigrant residences. In this latter situation, we presented the study to the children in the classroom and sent home an information sheet for the families. If parents wished to participate in the study, they contacted the study co-ordinator.

The data corpus includes interviews with 5 families from Haiti (H), 4 North African families (M), 5 Latin American families (LA), 1 Eastern European family (EE) and 23 French-speaking Quebec families (FQ). Alongside the immigrant/non-immigrant subgroup, families were included if their child was between 8 and 16 years of age, experiencing recurrent abdominal pain at least once a week over the last 2 months (following the ROME III paediatric criteria for gastrointestinal disorders; Rasquin et al. 2006). An extra criterion was required for families recruited in the community, as opposed to patients from the gastroenterology clinic: Families from the community were included if they did not seek or receive specialised gastroenterological care for their child’s pain in the past year. However, these families were not excluded if they occasionally visited various medical and allied health professionals.

A total of 81 interviews were conducted: 38 with families, 43 interviews with children (some families had more than one child with FGIDs). The family interviews lasted between 60 and 90 minutes, while the children’s interviews were shorter (25 minutes to 1 hour) respecting the child’s attention span. All interviews took place at the family’s home, upon the mother’s request. Interviews were carried out mostly in French and Spanish. Parents spoke French either as a second language or mother tongue. All the children interviewed attended French-speaking schools. Some Latin American families alternated between French and Spanish, as a team member was a native Spanish speaker. Interviews were audio-recorded and transcribed. Field notes documented observations on the family milieu, body language and social interactions between family members during the interview period.

Participation in the study was completely voluntary and consent was obtained from every family member (if they were old enough to understand the notion of consent). Children’s assent was obtained with the study explained in an age- and development-appropriate language. All participants either gave written or verbal consent and no family approached to take part in the study withdrew or refused to participate. The information gathered during these interviews was confidential. We did not share the children’s narratives with their parents, nor did we share results of any given family or patient with their healthcare provider. The study (and all relevant documents such as consent forms, information sheets and thematic interview guides) was approved by both the university and hospital ethics research board.

The data were gathered using an adaptation from the Turning Point/Period Interview (Corin et al. 2007), which is an ethnographic semi-structured interview guide compatible with our theoretical approach. The main interview themes included the onset, development, perception and expression of symptoms, explanations and meanings attributed to symptoms, treatments and experience of relationship with medical services. We also collected family histories and wider social and migration trajectories. For children...
and youth, the interview themes were similar to those for families, only presented in an age-appropriate manner accessible to children, always related to examples and experiences they put forth and having them detail them in whatever way they chose appropriate.

We used the signs, meanings and actions model (Corin & Bibeau 1992) to analyse parents’ and children’s perspectives regarding the manifestations of stomach aches, their meanings and the actions initiated to relieve pain. In this model, signs refer to the perception and expression of symptoms and nonsomatic experiences associated with them (Corin & Bibeau 1992). Taking into account the surrounding sociocultural contexts, the meanings and explanations reveal the child’s and parent’s representations of the symptoms as well as how these signs and meanings interact over time. Actions refer to the many different actions taken to relieve the child’s symptoms, whether at home, biomedical treatments or alternative therapies. The interviews underwent a thematic analysis, guided by our initial research questions and the signs, meanings and actions model discussed above. The data from the semiological (signs), interpretative (meanings) and pragmatic (actions) variables were cross-compared on three levels: between respondents within a family, between families of the same ethnic group (and more so between immigrants and non-immigrants) and between families who consulted the paediatric gastroenterology clinic in contrast to those who did not.

To protect the confidentiality of participants, the following data excerpts are labelled by the children and their parents’ ethnic origins appearing in brackets. All names are pseudonyms.

**Findings**

Beyond the immigrant and non-immigrant subgroups central to our study, three types of therapeutic spaces emerged from the parents’ and children’s narratives in relation to FGIDs. These paths to care are the home, complementary and alternative therapies and biomedical treatments. Many families (29 of 38), regardless of immigrant background or place of recruitment, turned to biomedical health services (paediatricians and GPs, hospital emergencies, as well as paediatric or paediatric gastroenterology clinics) at least once for their child’s stomach aches. However, fewer immigrant families (2/11) than non-immigrant families (9/11) were referred to a paediatric gastroenterology clinic. All families used home remedies, while a third of them also used alternative healing therapies.

**Relieving pain in the family space**

Every family in our study relied upon home remedies for partial and temporary relief from stomach aches. Rest was the most common treatment suggested by mothers or self-initiated by children, alongside dietary changes, attention-distraction strategies or the placement of a warm compress (hot-water bottle or warm towel) on the child’s abdomen.

Giving and receiving care for a stomach ache was often an opportunity for families to socialise more intimately. This form of caring may foster greater physical and emotional closeness between a mother and child. A child’s yearning for closeness for his/her mother characterised most immigrant families, a proximity that the mother wished to offer.

Often, when the girls don’t feel well, they get closer to me. I want to soothe the pain. It helps when they find affection, it soothes the pain. (Mother of Angela, 12 years and Laurie, 9 years, H)

Another mother stated:

They need me more when they are not feeling well. Children feel better when they receive love and affection. (Mother of Etienne and Elionie, 13 years and Magdala, 12 years, H)

This need for closeness extended to other family members, who shared medical or healing knowledge and advice. Aaron (8 years, LA) recalled that in Colombia, his grandfather gave him: ‘warm orange juice and honey with a spoon’. He, his sister and cousin used to take it to help relieve their stomach pains. Omar (13 years, LA) said that his relatives helped him considerably:

I had lots of aunts and uncles who gave me the same advice as my mother. So I had even more support.

Using medicinal herbs from their homeland was another way of strengthening and maintaining family connections across international borders. Merline (10 years, H) explained when she had a stomach ache, her mother made her tea from exotic fruit leaves sent over from Haiti or that were bought at the local Haitian market. Merline referred to this remedy as being ‘passed down from [her] parents and grandparents’, and given to her as a little girl.

Yet, for pain to be addressed, it first has to be acknowledged as ‘real’ pain. Some parents (8/38 families), the majority non-immigrants (7/8), doubted the authenticity of their child’s complaints. A child’s quest for legitimacy has been documented in the medical setting (Nettleton 2006, Jutel 2010), but less so within the family unit. In one family interview, mother of Jeanne (10 years, FQ) asked her if ‘it is
always really, really, really true’ when she said that she had a stomach ache or if it was a deceptive strategy to stay home from school. In another instance, father of Marc (9 years, FQ) mentioned that his son always said he was going to vomit when in fact, he never did. This lack of parental recognition of pain may lead to tensions within the family unit. Both Marc’s mother and father challenged his complaints and appeared impatient when their son raised the issue. Mother of Carl (9 years, FQ) warned her son that he would be ‘punished’ if he did not tell the truth. Another mother described that her daughter (Rose, 10 years, FQ) was manipulative because she ‘wants to stay home’ from school.

Families that attended the clinic also expressed a stronger need to identify the cause of their child’s pain. As mother of Guillaume (13 years) questioned:

When are they going to find out what he has? It makes me mad. It can be anything but find it. (Mother, FQ)

Turning to the biomedical healthcare services

Families attending the paediatric gastroenterology clinic were mostly French-speaking Quebecers (9/11) and shared certain behaviours. These families were more ready to report a feeling that something was wrong.

We have been seeing the paediatrician for some time now. André (7 years) has had blood tests, they analysed his stools and ran other tests. What I would like is food allergy testing and not only the most common allergies. I want them to find why André has this problem. (Mother, FQ)

Complementary and alternative therapies: beyond the home and biomedicine

One third of the families (12/38) from all backgrounds (immigrant and non-immigrant) used complementary and alternative treatments, such as meditation, acupuncture, prayer and massage therapy, at least once in the 2 months prior to our study. Most families perceived these therapies (provided outside the purview of biomedical health services) as adjuvants. In addition, these therapies were perceived as partial, offering temporary relief in comparison with a more formal, curative biomedical approach. However, among Haitian families, religion was considered essential and not necessarily as an adjuvant. For these families, the church represented a gateway for community life and social solidarity, as well as a place of healing and hope (Bibeau 2006, Gomez 2010). As mother of Lydie (13 years, H) recalled, prayers were a way of sharing suffering and hope. Prayers preceded medical consultations: ‘When we’re sick, before going to the doctor, we pray to God’. Some North African parents discussed the role of religion, similarly, although it was less pronounced and de-emphasised over biomedical health services.

Turning to the biomedical healthcare services

Families attending the paediatric gastroenterology clinic were mostly French-speaking Quebecers (9/11) and shared certain behaviours. These families were more ready to report a feeling that something was wrong.

We have been seeing the paediatrician for some time now. Andrée (7 years) has had blood tests, they analysed his stools and ran other tests. What I would like is food allergy testing and not only the most common allergies. I want them to find why Andrée has this problem. (Mother, FQ)
tainty regarding the best course of treatment for the pain and concern for potential complications:

Sometimes, the more we look for answers, the less we find them. It’s like with our daughter, we don’t want to lose her. Sometimes life brings you cancer or other problems you know? So when something happens, whooooo – what does she have? It makes us worry. (Father of Louise, 9 years, FQ)

Conclusion: the issues

In consideration of the signs, meanings and action model that guided our analysis, and the relationship between culture, subjectivities and life course events (Kleinman 1988, Bibeau & Corin 1995), our study suggests that culture (inclusive of social status, ethnic background, religion and gender), as well as interactions within families and clinical settings, significantly influence pathways to care.

Attempting to understand why parents of children with FGIDs seek medical attention while others do not, we must remember the social nature of all medical encounters, where children, parents and medical professionals engage and negotiate different illness experiences and explanatory models. These encounters are shaped by the opportunities afforded to children and their parents to discuss their problems in ways that both clinicians and families can understand, receptive to their individual backgrounds (Fortin et al. 2011). From this point of view, an important issue emerged from both children’s and parent’s narratives – the need for a therapeutic space that is receptive to the authenticity of a child’s complaints for gastrointestinal disorders. Perhaps non-immigrant FQ families find this receptiveness more easily within the clinical encounter (with gastroenterologists and GPs) and are therefore more comfortable seeking biomedical advice.

In general, immigrant families welcomed that their children sought care and attention from their parents. This attitude is fostered by relationships within the nuclear family, community networks (churches, friends) and/or the extended family. In our data, this form of receptiveness means allowing children to describe complaints in their own words, acknowledging their pain, diligently caring for them in a healthy (rather than tense) emotional atmosphere and allowing these children to temporarily withdraw from other social obligations (such as attendance at school). This may appear as parental indulgence that goes both ways: it could aggravate the condition by giving it undue importance or rewarding it (Walker et al. 2006). Research should further address this ambiguity regarding parental receptiveness to their children’s gastrointestinal complaints.

According to Zabalia (2007), to enable children to express their pain and intensity requires a complex intersubjective process involving the co-construction of a shared representation of pain. The formation of this ‘common ground’ demands a reciprocal adaptation when talking to children, allowing children and youth to express their sensory and emotional experiences. This requires that adults must put aside any preconceived ideas about the nature (real or imagined) and extent (normal or abnormal) of expressions of pain and listen to children speak about their experiences, as well as observe their attitudes and behaviour. Receptiveness within the family as well as in the clinical encounter accommodates the child’s experience without immediately labelling it as false or abnormal (Rosen 2006). Furthermore, being attentive to narratives in the clinical encounter allows patients to become partners in care (DelVecchio Good & Good 2003), acknowledging diversity in the individual and collective resources that children and families draw upon in their environments in coping with FGIDs. In addition to documenting the disparity between immigrant and non-immigrant families in a hospital clinic, the different pathways to care help us to understand these patient’s social world, while shedding light on the intricate relationships between values and social milieux, between culture, practice and the logics that guide individuals to act.

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Conflict of interest

None.

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