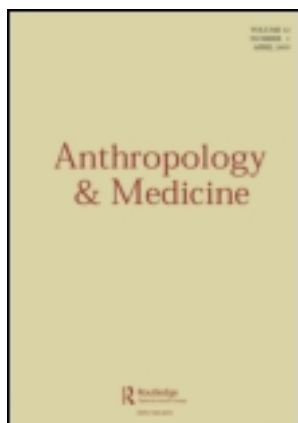


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Uncertainty, culture and pathways to care in paediatric functional gastrointestinal disorders

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This paper examines how children and families of diverse ethnic backgrounds perceive, understand and treat symptoms related to functional gastrointestinal disorders (FGIDs). It is questioned how different ways of dealing with medical uncertainty (symptoms, diagnosis) may influence treatment pathways. Semi-structured interviews were conducted with 43 children of 38 family groups of immigrant and non-immigrant backgrounds. The analysis takes into account (a) the perceived symptoms; (b) the meaning attributed to them; and (c) the actions taken to relieve them. The social and cultural contexts that permeate these symptoms, meanings and actions were also examined. It is found that, in light of diagnostic and therapeutic uncertainty, non-immigrant families are more likely to consult health professionals. Immigrant families more readily rely upon home remedies, family support and, for some, religious beliefs to temper the uncertainty linked to abdominal pain. Furthermore, non-immigrant children lead a greater quest for legitimacy of their pain at home while most immigrant families place stomach aches in the range of normality. Intracultural variations nuance these findings, as well as family dynamics. It is concluded that different courses of action and family dynamics reveal that uncertainty is dealt with in multiple ways. Family support, the network, and trust in a child's expression of distress are key elements in order to tolerate uncertainty. Lastly, the medical encounter is described as a space permeated with relational uncertainty given the different registers of expression inherent within a cosmopolitan milieu. Narrative practices being an essential dynamic of this encounter, it is questioned whether families' voices are equally heard in these clinical spaces.

Keywords: uncertainty; biomedicine; culture; signs; meanings; actions; pathways to care

Introduction

It churns, everything gets mixed up. (10 years - LA)

It's like being stabbed. (16 years - FQ - G)

It's like being hit by a ton of bricks. (10 years - FQ - G)

It's too much. You get a kind of ball in your stomach, it gets bigger and bigger.

(10 years - FQ)

Children with functional gastrointestinal disorders (FGIDs) talk about their abdominal pain in different ways: as diffuse or very sharp, often difficult to describe exactly. When asked

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what happens when she gets a stomach ache, one girl sets out the problem: 'I don't know how to explain it. In my head, I want to, but I can't put it into words. There are no limits!'

Given the typical absence of apparent organic lesions of the intestine, functional gastrointestinal disorders are studied largely from a biopsychosocial perspective (Drossman et al. 1999). Stressful situations or sensory stimuli may affect hormonal secretions, the degree of inflammation, gastrointestinal sensitivity and motility. These internal phenomena combine with individual characteristics (e.g., clinical history, distress) and social characteristics (e.g., norms, culture), to influence the behaviour of sufferers (Yamada 2005).

As in the wider area of the medically unexplained symptoms (MUS),¹ clinicians, patients and researchers remain uncertain about the nature, causes and treatment of FGIDs (Rosh 2010; Walker and Jones 2005). The Rome Foundation, an international non-governmental organization, provides assistance for the diagnosis and treatment of FGIDs. They identify four sources of uncertainty: (1) the absence of biological markers to define the pathology; (2) dissatisfaction with treatment; (3) not knowing what triggers the pain or whether it is serious; and (4) inability to control the pain (Drossman 2007). Similarly to MUS, the lack of diagnosis, prognosis or treatment creates 'embodied doubt and uncertainty' for those who experience FGIDs (Nettleton 2006, 1167).

The aim of this paper examines the experience of FGIDs amongst parents and children whose cultural backgrounds are as diverse as the care pathways they have followed. The analyses and discussion presented here stems from a collaborative paediatric and anthropology interdisciplinary study that set out to better understand the underrepresentation of immigrant children in the overall paediatric functional gastrointestinal disorders (FGIDs) patient population.² This paper presents a dual working hypothesis in that ways of coping with the uncertainty associated with FGIDs (1) influence families' pathways to care and (2) are coloured by socio-cultural backgrounds. The next section has a discussion of works that highlight the polysemic nature of uncertainty as well as the complexity and heterogeneity of its experience. The research protocol is then outlined, the study findings described, and uncertainty, culture and pathways to care are discussed. The conclusion reflects upon relational uncertainty, perhaps as an inherent attribute within clinical encounters in diverse social and cultural environments.

The complexities of uncertainty: from medical practice to patients' quests

In 1988, Renée Fox confirmed what other researchers had found previously: despite formidable scientific progress, the practice of medicine was permeated with insoluble uncertainty. She distinguished two types of uncertainty. The first results from the impossibility of being familiar with all medical knowledge and techniques. The second arises from the inherent limitations of medical science and the fact that there are questions about the human body that no doctor, however qualified, can solve. When she revisited her work in 2003, the literature revealed signs of deep uncertainty that went to the very foundations of medical thought. She wrote about the insistent questioning of the links between the scientific and non-scientific aspects of the practice of medicine; between theory and its applications; and between knowledge, perceptions and beliefs.

These thoughts have been further developed by many scholars, as medical uncertainty gives rise to a rich body of literature (Jutel 2010). For some, uncertainty regarding an illness adds to doctor's frustrations and makes patients more vulnerable (Crowley-Matoka et al. 2009). For others, interestingly, uncertainty has no *a priori* negative or positive value, other than what people make of it (Bateman 2010; Honkasalo 2006; McCormick 2002). Another group of scholars adopt a more critical approach, underlining how the

process of diagnosis is not 'simply the deciphering of symptoms and the application of objective medical categories' (Gardner et al. 2011, 844). Rather, this process reveals the different tensions in motion, stemming from an array of forces: from clinical protocols and medical authority to wider social norms and economic interests. For Babrow and Kline (2000), the desire to eliminate uncertainty is rooted in a belief system that holds medicine as an objective practice where causal determinism can be elucidated with certainty, and there is the possibility of developing definitive tests for specific diseases (the key to diagnosis and treatment). On the contrary Kirmayer et al. (2004, 664) point out that as medical knowledge and technology evolves, diagnosis uncertainty may diminish but that 'fundamental epistemological constraints on what can be known in the clinical context will persist'. Diagnostic systems are rooted in ideal types that can be very different from individual illness experiences, while clinical medicine applies general knowledge to specific patients. In line with Foucault's (1963) seminal work on the clinic, Good (1994) points out that the locus of disease remains within the anatomical body, both in medical and lay discourses. This said, both doctors and sufferers share in the hope that symptoms can be explained and treated.

Research in FGIDs shows that clinicians also share their patients' uncertainty. Nevertheless, a recent study conducted by the members of the North American Society for Paediatric Gastroenterology, Hepatology and Nutrition suggests that clinicians define FGIDs from a variety of points of view, often presuming that the pain is imagined (Schurman et al. 2010). By generating anxiety in clinicians who dread missing a biological cause, diagnostic uncertainty could be the reason for prescriptions and medical tests that some experts consider to be useless or even harmful. This problem, along with repeated visits to the doctor and unsatisfactory therapeutic relationships, has been amply documented (e.g., Talley 2004; Cash, Schoenfeld, and Chey 2002).³

At the same time, diagnostic and therapeutic uncertainty can make parents anxious, especially if they feel that doctors may be missing a serious illness causing their child's symptoms or if the doctor suggests that the symptoms are emotional and psychological. According to Boyle (1996), this climate of anxiety triggers or reinforces the child's pain, while denying the social recognition of their suffering (Dumit 2006). It may also be, as will be seen, a site of tension: not only between caregiver and sufferer, but amongst family members. At the same time, the symptoms are sometimes so distressing that parents have trouble accepting a diagnosis of functional disorder, which assumes a lack of biological pathology, making the problem a psychological one (Fortin, Gomez, and Gauthier 2013). According to Lindley, Glaser, and Milla (2005), some parents' complaints are manipulative, with the aim of avoiding a psychological interpretation of their child's symptoms. Instead of being reassured by the lack of pathology, these parents will ask for extensive medical investigation. In turn, this medical consumerism drags the child into a spiral of consultations.

Commenting on Lindley's paper, Eccleston (2005) brings up the question of therapeutic alliance in a context where patients and doctors complain about each other. Generally speaking, achieving a true partnership in specialized paediatric care is a complex matter, especially in regards to the respective expectations of parents, children and doctors and the social, cultural and economic forces at play (Fortin forthcoming). In cases of FGIDs, diagnostic and therapeutic uncertainty adds another dimension to this complexity. Studying the question from several complementary angles is essential to understand the clinical challenges identified by researchers. Youssef et al. (2006), Eccleston (2005) and Creed (1997) suggest that FGIDs researchers devote more time to the stories of people suffering from these disorders, in the same way perhaps as Good and Good (2000) or

Clifton-Soderstrom (2003) emphasize that narrative practices are an essential part of the clinical encounter. This study explores the narratives of children with FGIDs and also their parents' narratives, with a focus on how they construct their experiences.

Methods

FGIDs and uncertainty: exploring narratives

This exploratory study looked at a sample of 38 Montreal families of immigrant and non-immigrant background, representing a variety of pathways to care. Nine families were recruited in a paediatric gastroenterology hospital clinic, and the remaining 29 families were recruited in the community. The authors met with five families from Haiti, four from the Maghreb (North Africa), five from Latin America, one from Eastern Europe and 23 who were French-speaking Quebecers. These meetings led to a total of 81 interviews: 38 with families and 43 individual interviews with children.

Aside from diverse pathways to care and immigrant, non-migrant status (as well as ethnic background), the inclusion criteria required that children were between 8 and 16 years of age and had experienced regular abdominal pain over the last two months. For the families recruited in the community (as opposed to patients of the gastroenterology clinic), another criterion was the lack of specialized gastroenterological care for the pain. However, this did not exclude occasional visits to various medical and paramedical professionals.

The data were gathered using an adaptation of the Turning Point/Period Interview (Corin, Gauthier, and Rousseau 2007), an ethnographic semi-structured interview guide that was initially focused on illness episodes in the field of mental health. The authors adapted the guide to the problem of FGIDs in children. The main themes documented were the development, perception and expression of the children's abdominal pain; explanations and meanings attributed to the symptoms; treatment methods and the families' relationships with medical services. Narratives were collected by asking non-directive questions sensitive to an array of life situations.

The signs, meanings and actions model (Corin, Bibeau, and Uchôa 1992) was used for the analysis, in order to better understand the health care pathways of the participants. The semiological variables (signs) are the symptoms characterizing the child's experience of FGIDs. The interpretation variables (meanings) are the patients' and families' own representations of the onset and evolution of the symptoms. The pragmatic variables (actions) are the many different methods used to relieve the child's symptoms, whether home or medical treatments or paramedical services. In short, how one identifies different manifestations of 'stomach aches', as well as their meaning(s) and how one takes action to relieve the pain are socially and culturally based.⁴ This analytical model does not necessarily infer a linear model of explanation or action but suggests, rather, that all three dimensions must be examined in order to better grasp the trajectories at hand as well as the variations within each facet (Bibeau and Corin 1995).

In this perspective, the narratives underwent a thematic analysis, guided by the initial research questions and the signs, meanings and actions model. The data from the semiological, interpretative and pragmatic variables were cross-compared on three levels: between respondents in the same family, between families of the same ethnic group (and in a more inclusive way between immigrants and non-immigrants) and between families who consulted the paediatric gastroenterology department and those who did not. The findings are illustrated here by excerpts from the interviews labelled by the participants'

origins: H (Haitian), LA (Latin American), NA (North African), E (East European) and FQ (French-speaking Quebecer). The letter G indicates that the family consulted the paediatric gastroenterology clinic.

Results

Three main themes (semiological, interpretative and pragmatic) associated with uncertainty emerged: (1) the suspicion as to the authenticity of the symptoms and the trouble communicating about the signs; (2) the instability and plasticity of meanings; and (3) the variability of responses to abdominal pain.

Authenticity and communicability of signs

Parental accounts highlight areas of uncertainty regarding the authenticity of the pain. For example, in a family interview, the mother asks her daughter Jeanne⁵ (10 years, FQ) whether 'it is always really, really, really true' when she says she has a stomach ache, or whether sometimes it is because she has not done her homework and doesn't want to go to school. Marc's (9 years, FQ) parents say they don't always take his complaints seriously. According to Marc's father, Marc often says he feels sick to his stomach, that he is worried and afraid of vomiting, when in fact he never vomits.

Doubt about the authenticity of the pain creates tension within the family. For example, one mother asks her son Louis (9 years, FQ) to tell the truth about his stomach ache, or else he will be punished. Another mother also seems somewhat doubtful of her daughter Nadia's (10 years, FQ-G) complaints: 'I wasn't really worried because I thought she was just being manipulative, because she always wants to stay home with us. So it was an excuse.' Nadia's mother also admits becoming impatient with her daughter's complaints. Parents may think the child is faking, trying to get attention, being oversensitive or trying to get special treatment. In this study, this type of dynamic was found mostly amongst those who attended the paediatric gastroenterology clinic, mainly of French Quebec descent.

On the other hand, the children's accounts suggest that they are sensitive to these types of judgments and their moral implications. In fact, uncertainty seems to pave the way for a normative reading of the signs in all the families. When children notice such interpretations of their experiences, they may adopt strategies to protect themselves. For example, Alexandre (15 years, FQ-G) often misses school due to abdominal pain. Although he is reluctant to talk about this pain, he feels obliged to explain his absences to his schoolmates: 'I make up reasons because I don't always want to tell them I was at home in bed [. . .]. I mostly say that to guys to seem tougher.'

For Lina (10 years, NA), it is a question of maturity. She does not talk about her abdominal pain when it occurs at school, for fear her teacher will chide her: 'I keep it to myself. The teacher said: "You have to act grown up. I'm not a doctor". So I'd rather not say anything. I don't want any trouble.' This ideal of maturity does not call into question the truth of the complaints, but underscores the school's and, more broadly, society's, normative expectations of the model child. Complaining is seen as failing to be as grown up as children of their age should be. As a result, Lina only complains at home, where her mother actively responds.

Rita (9 years, FQ) relates how she had forgotten a book for school and, as punishment, had to copy a sentence over and over. She found it unfair and while she was writing her lines, she got a stomach ache: 'All of a sudden, on my tenth line, I got a pain. The teacher

said: “Oh! It’s just because you don’t feel like doing it. Go back to your seat.” So I had to. I was really shocked because she knew all about it. My dad had written a letter.’

In emphasizing the fact that her teacher did not believe her, Rita not only alludes to the suspicion of her complaint, but also to the little weight given to her father’s letter, which was meant to inform the school staff that she was sometimes inconvenienced by sudden, unexplained pain. Ever since then, whenever Rita is in pain, she tries to soothe herself on her own, telling herself: ‘It will go away’.

Uncertain meanings

You’re always trying to figure out what it is. If it’s cramps, it’s painful. You start imagining things. You’re always trying to figure it out. What did I give her to eat? Is that what it is? You let your imagination run wild. I wonder if it’s germs. I don’t know. I wonder, is it because of the environment? (Mother, H)

As this mother suggests, in trying to figure out what the symptoms mean, parents come up with all sorts of tentative explanations. Food, stress, heredity and an underlying disease were the main explanations mentioned by the families, always framed with uncertainty. Food, for example, is often questioned, but no consensus is achieved between and within groups as to what is ‘good food’. For some, the good food is ‘traditional’ and the bad food is ‘local’. For others, good or bad food practices may be features of the same food, within a given family.⁶

Parents generally recognize that the meanings are only tentative, but those who attend the paediatric gastroenterology clinic seem to find the tentativeness harder to accept. For example, Alexandre (15 years, FQ-G) had an ultrasound that showed swollen lymph nodes. His mother keeps wondering about the swelling: ‘Why? There’s never been an answer. Why? No one has ever been able to answer my question: Why are they swollen?’ Alexandre’s father expresses his disappointment in the physician they met: ‘The gastroenterologist hasn’t found the cause, he just orders tests.’ Because the tests for Alexandre have not found any biological lesions, his mother is waiting for more conclusive answers: ‘We’re waiting for the doctor to say something, find something. I hope they find something. I don’t care what, as long as they find something’ (Mother, FQ).

At the same time, when they do not know what is happening, parents may tend to put their children’s abdominal pain in the context of different types of gastrointestinal disorders in their families. Accordingly, mothers may try to understand their children based on their family history or narrative that they construct after the fact. So, worried about the possibility that her son might develop cancer unknown to the doctors, Alexandre’s mother sees a connection between this worry and her own history. Chloé’s mother believes that her daughter (8 years, FQ) has the same attitude as she does and thus fears that Chloé, like her, will develop fibromyalgia: ‘I watch for signs, then I say, “Can it be that? Does she have an irritable bowel?”’ (Mother, FQ).

Most of the children associate the occurrence of their pain with an unpleasant or restrictive situation. Jeanne (10 years, FQ), for instance, talks about the pain and nervousness she feels when she thinks she has hurt someone: ‘I don’t like hurting anyone, but sometimes I do it by accident and sometimes I get a stomach ache because I’m stressed out.’ Natalia mentions situations she associates with her pain and concludes with, ‘I don’t like something, then I’m nervous because I don’t like it’ (8 years, LA). Gabriel says he is starting to get stomach aches when he is mad at his father or when he cannot manage to

do something he must or should do: ‘Sometimes I get mad when I can’t do something because I don’t like it’ (9 years, LA).

In these narratives, it is not clear where a stomach ache starts and ends: the discomfort seems to extend beyond the abdominal region. Catherine (13 years, FQ) speaks of anxiety accompanied by overwhelming thoughts, which she associates with her nausea and fear of vomiting. When trying to be more specific about her experience, she says ‘I don’t know what’s going to happen, I’m heading into the unknown.’ The occurrence of abdominal pain in unfamiliar situations is also mentioned by other children. Léo states ‘At school there are guys who are kind of a threat to me because sometimes they hit me’ (10 years, FQ). Making the link to his abdominal pain, he adds that it is stressful ‘because no one knows what’s going to happen, no one knows’.

Yet other accounts argue against this association. For instance, during the interview, one Mathieu’s (10 years, FQ) mother asks her son: ‘Is it related to when you have something hard, like a test, coming up? Something you don’t necessarily feel like doing?’ Mathieu answers: ‘That’s not it’. He says he has even had a stomach ache in computer science, and he loves computer science. For Mathieu, this disproves his mother’s suggestion that his stomach ache is related to constraints of everyday life. Similarly, Carina (10 years, FQ/LA) says: ‘It can happen anytime, so I don’t really know. It doesn’t happen at any special time. I’m not doing anything special, anyway. I’m just eating or sitting in class writing. Then it just happens.’ These excerpts show that the meanings of abdominal pain relate to multiple dynamics that have yet to (or perhaps cannot) be fully revealed and decoded.

An array of actions: from home treatments to a quest for expertise

The narratives highlight three main therapeutic spaces where efforts are made to relieve the pain: home, alternative therapies (e.g., acupuncture, alternative medicine, religion) and medical consultations. All the families use some form of home treatment, such as rest, dietary changes, herbal tea, or a warm towel or hot-water bottle on the child’s abdomen. ‘As did my parents and my grandparents, when someone has a belly ache, we give him tea, we brew orange leafs’ (Mother, H). Such forms of treatment are not merely instrumental, they also have a relational quality. They may foster emotional closeness between mother and child. ‘Often, when the girls don’t feel well, they get close to me. I want to sooth the pain. It helps when they find affection, it soothes the pain’ (Mother H). Other ways of dealing with FGIDs create tension in the family or lead a child to go off by himself: ‘When I have a stomach ache, I don’t want anyone to talk to me’ (Marc, 15 years, FQ)

In some households, an extended family support system is involved in care, with relatives offering advice and know-how. For example, Gabriel (9 years, LA) has a cousin who also used to suffer from abdominal pain. His mother points out how she and her sister-in-law have been able to help each other: ‘Her mum and I have tried out remedies together, and all that . . . We’ve supported one another’ (Gabriel’s mother, LA). This type of support system seems to occur more often, extensively and appreciated in immigrant families. In these families, distributing care amongst relatives seems to counteract the uncertainty, at least up to a certain point, by developing parents’ confidence in their own ability to protect their children’s health.

In addition to providing home remedies, one third of the families also seek help from non-medical resources, which are generally used as adjuvants and complement other forms of treatment. Although such resources do not usually hold much weight in family

life, religion is an exception for Haitian families, for whom prayers are intricately woven into treatment. 'When we're sick, before going to the doctor, we pray to God. I think God is the only one who can cure me and then the doctor with his medication can help' (Mother, H). The narratives of Haitian mothers indicate that religious practices are the primary response to their various life difficulties. 'We pray, and God does something. Because I have faith in Him' (Mother, H).

The decision to see a health-care professional is always made when the parents are at a loss of what to do. 'I panic. I don't know what else to do,' says Sara's mother (NA). Seeing a doctor rarely eliminates this uncertainty, even when medical tests are done or medical advice is given. This situation puzzles parents, like Victoire's mother (G): 'They told me they couldn't find anything, that everything was all right, but she still has stomach aches' (Mother, G). And Jessica's mother states: 'They say, "It's all right, there's nothing. Maybe it's because she's constipated?" But she's never been constipated. Never! That's not it' (Mother, FQ). The unresolved nature of the pain can be a real trial that challenges all the family's resources. Some parents reveal a terrible feeling of helplessness at having exhausted all the resources available to them. Jessica's mother, for example, says she feels helpless at dealing with her daughter's illness. She doesn't know what to do about it. Feeling powerless, she says the pain is part of life and simply has to be endured.

Families run up against both diagnostic and therapeutic limitations when seeking help for their children's abdominal pain. The narratives reveal two contrasting strategies in dealing with these limitations, adopted by families to varying degrees. The first is to doubt the need to seek medical help. Accordingly, some families express scepticism as to whether seeing a doctor about the pain is appropriate or useful. Victoire (13 years, H), relates how she ended up lowering her expectations: 'They never found out what was wrong or why I had it, so, no, I don't think they're going to find out what I've got.' The second strategy, in contrast, consists of persevering in the search for medical expertise. In fact, uncertainty coupled with dissatisfaction makes some parents more likely to seek other forms of expertise. For example, faced with his son's repeated complaints and the lack of satisfactory answers from their family physician, Marc's (9 years) father thinks it is time to turn to specialists: 'We need to consult other people, to find out, as they say, why it hurts' (Father, FQ).

Uncertainty, culture and pathways to care

The signs, meanings and actions model advocates an intricate relationship between culture (in an inclusive perspective), meanings, subjectivity and life course events (Bibeau and Corin 1995; Kleinman 1988; Good 1977). It is a contribution to the study of illness as it attempts to reconcile the biological, social and cultural bodies (Lock 2002). In Bibeau's former work (Corin et al. 1990), the model gives way to a set of coherent semantic configurations articulated around organizing nodes. In this study, the authors thought the model useful in deciphering the narratives of families and children, in regards to FGIDs. As uncertainty became a major theme in the data (an organizing node), the authors hoped to elicit its influence on pathways to care. The authors were also curious about how ethnicity comes into play in how one deals with FGIDs. With immigrant families and children being very few in FGID clinics although FGIDs have no cultural or ethnic boundaries, the quest was set.

The authors' analyses led to the following observations. First, parents who expressed doubts about the authenticity of their child's expression of pain were surprisingly mostly non-immigrants, of French Quebec descent. Although much is said in the literature in regards to the non-recognition of FGIDs (and more widely MUSs) and the quest for

legitimacy of the sufferer in the clinic (Jutel 2010; Nettleton 2006) or as Dumit (2006, 578) says 'illnesses you have to fight to get', this legitimacy was not or less addressed (to the authors' knowledge) within the family and more often questioned in the clinical encounter. This study reveals how some children encounter belief barriers at home (and at school) even before any official health care is sought. Gamon's (2010) study amongst French-Quebecer children reveals similar findings. The authors also found much tension amongst members of these families and fear that abdominal pain indicates a more serious health problem. Is this what leads them to consult FGID specialists more than others? To echo Bauman (1991) who argues that the need for control over disorder may generate more disorder and the more we 'know', the more we have trouble accepting uncertainty (see Nettleton 2006 on this issue), the French Quebecer families the authors met with have a distinct profile in regards to how they negotiate signs and meanings, especially amongst those who consult the paediatric gastroenterology clinic. Secondly, the narratives suggest that immigrant families have more extended families and social networks. These resources seem to increase families' confidence in their ability to help their children. They also seem to ease the uncertainty and anxiety often associated with FGIDs. For Haitian families in particular, the church is a gateway to community life and social solidarity as well as a place of healing and hope for those struggling with health problems (Gomez 2010; Bibeau 2006).

Stemming from the accounts of children and their parents, these observations shed light on the initial hypothesis. They suggest that the mutual aid, advice and transmission of know-how within family or social networks (and religious communities) strengthen, to a degree, families' confidence in the possibility of achieving better general well-being. Those who benefit from such resources also seem to arrive at a less extreme relationship with uncertainty.

Whether signs are explained by food intake, stress induced by school expectations or heredity, most immigrant families are less inclined to identify the stomach aches as abnormal or pathological. The stomach pain blends into other daily concerns. Anastasia (16 years, E) sees her pain as 'part of me'. Her father, who, like his own father, suffers from irritable bowel syndrome, would like her to undergo medical investigation. Anastasia doesn't want to, saying her family doctor 'can't help me'. Her parents try different home remedies that have been beneficial by the past to the father and grandfather. The mother also remembers consulting a doctor when Anastasia was younger: 'He was a professor. He said "it's the baby's nature. Leave her be. It's part of her development"' (Mother, E).

In contrast, families who consult health services or the gastroenterology clinic more readily report a feeling of something being wrong, as well as family tensions, a stronger need to identify the cause of the pain, powerlessness or unconfirmed fears that the pain indicates a serious illness. In this regard, seeking medical expertise is linked to how signs are interpreted as well as to the adverse affects that FGIDs have on families' personal and social lives (Banez 2002; Rasquin-Weber et al. 1999)

Concluding remarks

Beyond the intercultural variations the narratives have brought to light, this analysis shows that uncertainty is a space into which parents and children can project their fears, anxieties and desires. No matter whether they accept or doubt their child's complaints, whether they insist on trying to find out the cause, whether they rely more on inner resources, extended family, friends, the community, or experts, both parents and children take variable positions towards uncertainty. As shown by the narratives (and the interview dynamics), questions pertaining to the general well-being of both children and parents allow and perhaps favour the sharing of different points of view. From this perspective,

uncertainty can also be seen as a positive force for families' searching for meaning and care. As for pathways to care, the family network support, one's capacity to negotiate uncertainty and, in some ways, trust in the child's expression of distress, seem to be key features in the necessity felt by parents and children to reach certainty, while everyone wishes to alleviate pain.

Lastly, and somewhat beyond the scope of this paper, the authors question the qualities of the encounters with healthcare professionals, as most families did seek medical advice at one or another time. Half of the families of all backgrounds who consulted general health services recall being told either that there was nothing wrong with their child, or that it was a mild case of reflux, a stomach bug, or anxiety. They were dissatisfied with the prescribed medication or advice as the pain was still there. All narratives reveal uncertainty as to the *a propos* of the medical advice they received. However, this study did not document these encounters directly (no observations were done in the clinic). But as the wider literature supports, narrative practices in the clinic are an essential part of the medical encounter (Good and Good 2000). It is not only a question of sharing the family's and children's concerns but also how this sharing is done, in ways that make sense for both patients and clinicians, given their respective backgrounds (Fortin, Rietmann, and Duclos 2011). Families may not have equal voices as they may not express themselves in the appropriate manner in the medical milieu. Uncertainty, then, is not only associated with medical practice, symptoms, diagnosis, prognosis and treatment. It can also be relational, and here migrant families may be at a disadvantage given culturally invested modes of expression and the symbolic resources they may or may not have.⁷ This is not a call for a 'culturally competent' practice but rather a practice that is open to diversity rather than being couched in one specific approach. In a cosmopolitan milieu, ethnic, religious and social diversity readily shatters preconceived patterns of culture as bounded systems linked to specific places and groups (DeVecchio et al. 2011). The clinic becomes a place of learning, a place where narratives are an essential pathway in moving beyond the evidence, or lack of evidence as in FGIDs. Uncertainty becomes an ally in this quest, far beyond medically unexplained symptoms.

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Notes

1. According to Kirmayer et al. (2004), patients with MUS in Denmark, UK and Canada account for 15% to 30% of all primary care consultations.
2. Montreal is a cosmopolitan city that welcomes between 30,000 and 40,000 immigrants each year from over 100 different countries. Even though 31% of the population is born abroad, only a small percentage (9%) of those patients of a paediatric gastroenterology hospital clinic seeking consultations for symptoms associated with FGIDs are immigrants (Caplan, Walker, and Rasquin 2005). The prevalence rates of FGIDs are 13–20% in the general Canadian population, 10–15% in the global population, and approximately 10% in the paediatric population (Fortin et al. 2013).

3. This body of literature is not unique, although important, as other voices in the field of FGIDs advocate for more nuanced approaches (Faure forthcoming).
4. One could also say 'politically' from a critical standpoint.
5. All names are pseudonyms.
6. See Roy (2002) on the political and identity features of food practices.
7. By symbolic resources, the authors intend social recognition attributed to the individual, based on his or her social position and the value attributed to this position within a given context. For further discussion on this topic, see Fortin (2008).

References

- Babrow, A. S., and K. N. Kline. 2000. "From 'Reducing' to 'Coping With' Uncertainty: Reconceptualizing the Central Challenge in Breast Self-Exams." *Social Science & Medicine* 51 (12): 1805–1816.
- Bateman, S. 2010. "À propos de l'incertitude dans la pratique médicale." *Sciences Sociales et Santé* 28 (1): 71–80.
- Bauman, Z. 1991. *Modernity and Ambivalence*. Cambridge: Polity Press.
- Banez, G. 2002. "Recurrent Abdominal Pain in Children and Adolescents: Classification, Epidemiology, and Aetiology/Conceptual Models." *Digest*, Spring: 24–26.
- Bibeau, G. 2006. "Les Églises noires de Montréal: une voie vers la citoyenneté?" *Anthropologie et sociétés* 30 (1): 202–211.
- Bibeau, G, and E. Corin. 1995. "Culturaliser l'épidémiologie psychiatrique. Les systèmes de signes, de sens et d'actions en santé mentale." In *La construction de l'anthropologie québécoise*, edited by F. Trudel, P. Charest and Y. Breton, 211–227. Québec: Les Presses de l'Université Laval.
- Boyle, J. T. 1996. "Abdominal Pain." In *Walker's Pediatric Gastrointestinal Disease: Physiology, Diagnosis, Management*, edited by R. E. Kleinman, 234. Hamilton, Ontario: Decker.
- Cash, B. D., P. Schoenfeld, and W. D. Chey. 2002. "The Utility of Diagnostic Tests in Irritable Bowel Syndrome Patients: A Systematic Review." *American Journal of Gastroenterology* 97 (11): 2812–2819.
- Clifton-Soderstrom, M. 2003. "Levinas and the Patient as Other: The Ethical Foundation of Medicine." *Journal of Medicine and Philosophy* 28 (4): 447–460.
- Corin, E., G. Bibeau, R. Laplante, and J. C. Martin. 1990. *Comprendre pour soigner autrement: repères pour régionaliser les services de santé mentale*. Montréal: Les Presses de l'Université de Montréal.
- Corin, E., G. Bibeau, and E. Uchôa. 1992. "Articulation et variations des systèmes de signes, de sens et d'action." *Psychopathologie Africaine* 23 (2): 183–204.
- Corin, E., A. Gauthier, and C. Rousseau. 2007. "Le médicament, ses reliefs et ses ombres sur la scène de la clinique transculturelle." *Revue Canadienne de Santé Mentale Communautaire* 26 (2): 37–52.
- Caplan, A., L. Walker, and A. Rasquin. 2005. "Validation of the Pediatric Rome II Criteria for Gastrointestinal Disorders Using the Questionnaire on Pediatric Gastrointestinal Symptoms." *Journal of Pediatric Gastroenterology and Nutrition* 41: 302–316.
- Creed, F. 1997. "Who Needs a Doctor for IBS?" *Gut* 41 (3): 415–416.
- Crowley-Matoka M., S. Somnath, S. K. Dobscha, and D. J. Burgess. 2009. "Problems of Quality and Equity in Pain Management: Exploring the Role of Biomedical Culture." *Pain* 10 (7): 1312–1324.
- Delvecchio Good, M. J., S. S. Willen, S. D. Hannah, K. Vichery, and L. T. Park eds. 2011. *Shattering Culture*. New York: Russell Sage Foundation.
- Drossman, D. A. 2007. "Introduction. The Rome Foundation and Rome III." *Neurogastroenterol Motil* 19: 783–786.
- Drossman, D. A., F. H. Creed, K. W. Olden, J. Svedlund, B. B. Toner, and W. E. Whitehead. 1999. "Psychosocial Aspects of the Functional Gastrointestinal Disorders." *Gut* 45 (2): II25–II30.
- Dumit, J. 2006. "Illnesses You Have to Fight to Get: Facts as Forces in Uncertain, Emergent Illnesses." *Social Sciences and Medicine* 62: 577–590.
- Eccleston, C. 2005. "Managing Chronic Pain in Children: The Challenge of Delivering Chronic Care in a 'Modernising' Healthcare System." *Archives of Disease in Childhood* 90: 332–333.
- Faure, C. forthcoming. "Désordres fonctionnels gastro-intestinaux." In *Gastroentérologie pédiatrique*, edited by F. Gottrand, and D. Turck. Paris: Doin Éditeur.

- Fortin, S. forthcoming. "Conflits et reconnaissance dans l'espace social de la Clinique. Les pratiques cliniques en context pluraliste." *Anthropologie et sociétés* 37 (3).
- Fortin, S., L. Gomez, and A. Gauthier. 2013. "Functional Gastrointestinal Disorders: An Anthropological Perspective." In *Pediatric Neurogastroenterology. Gastrointestinal Motility and Functional Disorders in Children*, edited by C. Faure, C. DiLorenzo and N. Taphar, 71–76. New-York: Springer.
- Fortin, S., M. Rietmann, and V. Duclos. 2011. "Toutes les familles ont-elles une même voix en contexte de soins?" In *Familles d'origine immigrante: polysémie des pratiques sociales. Enjeux sociaux, de santé et d'éducation*, edited by F. Kanouté, and G. Lafortune, 11–28. Montréal: Presses de l'Université de Montréal.
- Fortin, S. 2008. "The Paediatric Clinic as Negotiated Social Space." *Anthropology and Medicine* 15 (3): 175–187.
- Foucault, M. 1963. *La naissance de la clinique*. Paris: Presses Universitaires de France.
- Fox, R. C. 2003. "Medical Uncertainty Revisited." In *Gender, Health, and Healing: The Public/Private Divide*, edited by G. Bendelow, M. Carpenter, C. Vautier, and S. Williams, 236–252. London and New York: Routledge.
- Fox, R. C. 1988. *L'incertitude médicale*. Paris: L'Harmattan & Louvain-la-Neuve.
- Gardner, J., K. Dew, M. Stubbe, T. Dowell and L. Macdonald. 2011. "Patchwork Diagnoses: The Production of Coherence, Uncertainty, and Manageable Bodies." *Social Sciences & Medicine* 73 (6): 843–850.
- Garnon, G. 2010. "Circulation symbolique des désordres fonctionnels gastro-intestinaux." MSc diss., Université de Montréal.
- Gomez, L. 2010. "Les mots de ventre des enfants haïtiens de Montréal: entre la recomposition culturelle et souffrance familiale". MSc diss., Université de Montréal.
- Good, B. J., 1977. "The Heart of What's the Matter: The Semantics of Illness in Iran." *Culture, Medicine and Psychiatry* 1 (1): 25–28.
- Good, B., 1994. *Medicine, Rationality and Experience*. Cambridge: Cambridge University Press.
- Delvecchio Good, M. J., and B. Good. 2000. "Clinical Narratives and the Study of Contemporary Doctor-Patient Relationships." In *The Handbook of Social Studies in Health and Medicine*, edited by G. L. Albrecht, R. Fitz-Patrick and S. C. Scrimshaw, 243–258. London: Sage Publications.
- Honkasalo, Marja-Liisa 2006. "Fragilities in Life and Death. Engaging in Uncertainty in Modern Society." *Health, Risk and Society* 8 (1): 27–41.
- Jutel, A. 2010. "Medically Unexplained Symptoms and the Disease Label." *Social Theory & Health* 8 (3):229–245.
- Kirmayer, L., D. Groleau, K. J. Loper, and M. D. Dao. 2004. "Explaining Medically Unexplained Symptoms." *Canadian Journal of Psychiatry* 49 (10): 663–671.
- Kleinman, A., 1988. *Rethinking Psychiatry: From Cultural Category to Personal Experience*. New York: The Free Press.
- Lindley, K. J., D. Glaser, and P. J. Milla. 2005. "Consumerism in Healthcare can be Detrimental to Child Health: Lessons from Children with Functional Abdominal Pain." *Arch Dis Child* 90 (4): 335–337.
- Lock M. 2002. "Medical Knowledge and Body Politics." In *Exotic No More: Anthropology on the Front Lines*, edited by J. MacClancy, 190–208. Chicago: Chicago University Press.
- McCormick, K. M. 2002. "A Concept Analysis of Uncertainty in Illness." *Journal of Nursing Scholarship* 34 (2): 127–131.
- Nettleton, S. 2006. "'I just want permission to be ill': Toward a Sociology of Medically Unexplained Symptoms." *Social Sciences and Medicine* 62 (5): 1167–1178.
- Rasquin-Weber A., P. E. Hyman, S. Cucchiara, D. R. Fleischer, J. S. Hyams, P. J. Milla, and A. Staiano. 1999. "Childhood Functional Gastrointestinal Disorders." *Gut* 45 (Supplement 2): 1160–1168.
- Roy, B. 2002. *Sang sucré, pouvoirs codés, médecine amère. Diabète et processus de construction identitaire: les dimensions socio-politiques du diabète chez les Innus de Pessamit*. Québec: Les Presses de l'Université Laval
- Rosh, J. R. 2010. "Recurrent Abdominal Pain and the Pediatric Gastroenterologist: How Are We Functioning?" *J Pediatric Gastroenterol Nutr* 50 (1): 6–7.
- Schurman, J. V., L. H. Heather, and A. F. Craig. 2010. "Conceptualization and Treatment of Chronic Abdominal Pain in Pediatric Gastroenterology Practice." *Journal of Pediatric Gastroenterology and Nutrition* 50 (1): 32–37.

- Walker, L. S., and D. S. Jones. 2005. "Psychosocial Factors: Impact on Symptom Severity and Outcomes of Pediatric Functional Gastrointestinal Disorders." *Journal of Pediatric Gastroenterology and Nutrition* 41 (1): 51–52.
- Talley, N. J. 2004. "Unnecessary Abdominal and Back Surgery in Irritable Bowel Syndrome: Time to Stem the Flood Now?" *Gastroenterology* 126 (7): 1899–1903.
- Yamada, T. 2005. *Handbook of Gastroenterology*. Philadelphia: Lippincott Williams & Wilkins.
- Youssef, N. N., T. G. Murphy, A. L. Langseder, and J. R. Rosh. 2006. "Quality of Life for Children with Functional Abdominal Pain: A Comparison Study of Patients' and Parents' Perceptions." *Pediatrics* 117 (1): 54–59.