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Parallel vigilance: Parents' dual focus following diagnosis of Type 1 diabetes mellitus in their young child

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Abstract

There is consensus that enabling patient self-care and expertise leads to better management of chronic illness. Clinicians are being encouraged to manage clinical encounters in ways that promote these outcomes rather than perpetuate hierarchical relationships. This article describes one part of a larger study of 55 outpatient consultations conducted within 14 months of the diagnosis of Type 1 diabetes mellitus in young children. Participants were parents and the specialist doctors, nurses, dieticians and social workers who oversee the child's secondary care. Consultations were audio-recorded and transcribed. Our analysis draws on aspects of conversation analysis (CA) to investigate how parents' talk enacts a growing confidence in the management of their child's disease in the face of questioning from professionals. Analysis reveals how this talk distinguishes a duality of focus that combines the normal watchfulness exhibited by all parents as they protect their children, with an

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additional intense, parallel watchfulness for signs of potentially serious manifestations of diabetes. We term this phenomenon parallel vigilance and illustrate its development using five representative extracts from consultations. The concept of parallel vigilance extends the chronic illness literature and informs our understanding of a process that contributes to parents' developing expertise and provides new and important insights into the way in which parents conceptualize and implement their evolving role in the care of their child. Moreover, parallel vigilance serves as an enabler of parental contributions to the specialist consultation.

Keywords

chronic illness, conversation analysis, parallel vigilance, parent–clinician communication, Type 1 diabetes consultation

Background

Diabetes[1] is the most common endocrine disorder of childhood in industrialized countries (SEARCH, 2006) and is characterized by a life threatening derangement of glucose metabolism for which there is no cure. Following diagnosis, the complex therapeutic regimen required to maintain health includes frequent blood glucose monitoring and insulin injections. These life-sustaining activities pose a major challenge to the ability of parents to manage their child's disease (ADA, 2005; Swift, 2009).

As with other chronic diseases (Taylor and Bury, 2007), debate has focused on how social environments shape illness-related experiences and the extent to which individual responses define health outcomes (Gonder-Frederick et al., 2002; Rubin and Peyrot, 1992). This is particularly important with a rising burden of chronic diseases (WHO, 2002) that require complex responses over extended periods, which challenge health care systems (Nolte and McKee, 2008).

Diabetes: policy and care

Self-management has been emphasized as an important part of the management of chronic diseases (Nolte and McKee, 2008). Self-management support programmes (Department of Health (DoH), 2001a) and policies (DoH, 2001b, 2003, 2005a, 2005b) coupled with innovative learning theories (Rijken et al., 2008) provide interventions for those with a range of chronic diseases. With a focus on the patient (parent) management as 'lay expert', programmes addressing self-management of diabetes are included in the English Department of Health, *National Service Framework for Diabetes* (DoH, 2001b, 2007), the American Diabetes Association (ADA) Care Statement (2005) and the recent International Society for Paediatric and Adolescent Diabetes (ISPAD) Clinical Practice Guidelines (Swift, 2009). These policies promote care appropriate to the age and stages of the child's development.

Much of the intensive management of children with diabetes takes place outside the specialist consultation. Parents are encouraged to analyse their child's data, identify patterns and problem solve based on an understanding of insulin response, food intake, growth, activity and concurrent illness (ADA, 2005; DoH, 2001a). As a result, two intertwining dimensions of shared knowledge intersect: the resources arising from evolving experiences of disease self-management and the developmental process of medical knowledge and expertise in response to self-assessment (Paterson and Thorne, 2000). Acquiring this level of diabetes knowledge may blur the conventional boundaries between professionals (whose status is based on ownership of an exclusive body of expert knowledge) and formerly non-expert lay people (such as parents) (Candlin and Candlin, 2002). Nevertheless, the consequences of parental self-management contribute greatly to the shared experiences (Anderson, 2001) discussed during the consultation and form elements within the trajectory of lay expertise (Sarangi and Clarke, 2002) that we will present below.

Patient expertise

Prior (2003) traces the concept of lay expertise between 1970–2000 and asserts that although lay expertise is somewhat limited,[2] patients do have knowledge and experience to impart, and as such, they are 'experts by virtue of having experience in the use and expression of knowledge in particular contexts and circumstances … with the worthy aim of ensuring participation and consultation … in matters to do with medicine' (2003: 53). Donaldson (2003) concluded that:

> the patient as expert and partner in care is an idea whose time has come, and has the potential to create a new generation of patients who are empowered to take action to improve their health in an unprecedented way. (2003: 1280)

In parallel, other researchers have considered professional expertise to include not only discipline-specific practices and behaviours, but the management of interactional, co-participative practices (Candlin and Candlin, 2002; Candlin, 2002; Sarangi, 2001, 2005; Sarangi and Clarke, 2002) that result in shared decision making and patient centred health care delivery. This combined expert-knowledge-in-action (Sarangi, 2001) is a response that Peräkylä (2006) described as 'an encounter between two differently but equally resourceful agents where they negotiate diagnosis and treatment. In an ideal case, the parties' views will merge' (2006: 214). A focus on the manifestations of expertise displayed by health professionals and by parents of a child with a chronic disease provides an opportunity to re-examine expert lay knowledge in the context of the specialty-medical consultation.

Positioning vigilance and diabetes

Kepreotes and Keatinge (2010) conducted a metasynthesis of qualitative literature published between 2000 and 2009 that explored parents' experiences of parenting a child with a chronic health condition. Key findings describe parents' ongoing grief relating to diagnosis and beyond, lack of information and the inadequacy of relationships with professionals. In addition, they highlighted the ongoing process of change and adaptation associated with chronic diseases and the need to focus on communication, support and understanding between the child, parents and health professionals.

Adaptation to the ongoing, lifelong process of evolving care of diabetes is built on continuous vigilance by parents, children and their families. This vigilance is identified in the first of three articles in which Sullivan-Bolyai et al. (2002) examined mothers' daily experiences raising very young children with and without diabetes. Using questionnaires and interviews, the researchers evaluated mothers' daily management with specific attention to concerns and stress, routine and development, mother–child interactions and use of resources. They revealed how many of the problems facing mothers relate to their fear of hypoglycaemia, a life threatening side-effect of insulin therapy demanding constant vigilance. In a later article, Sullivan-Bolyai et al. (2003a) focused on descriptions of a typical day in which mothers describe 'constant and hyper-vigilance' (2003a: 24), as being in the foreground of their daily care. In a follow-up article, Sullivan-Bolyai et al. (2003b) described the approaches mothers use to become skilled in diabetes-related care. Soltesz (2003) proposed that 'the never-ending daily demands of living with diabetes' results in 'eternal vigilance' (2003: 449).

Most studies of parental vigilance have been based on interviews, surveys, narrative analysis and assessment instruments to measure diabetes self-management (Schilling et al., 2002). There appears to be little work focused on what actually occurs within the consultations as health professionals interact with parents of very young children with diabetes. Specifically, none focus on how parents describe in their own spontaneous words their clinical observations, their subsequent medical choices and the construction of their ultimate decision making. Our analysis addresses this deficit. We examine the evolution of parents' clinical knowledge and we argue that parallel vigilance is a manifestation of parents' knowledge and experiences, and its use, as a diagnostic resource, is an important feature of developing parent management and expertise.

Methods

This article is part of a larger study of 55 consultations that examined how health professionals enabled parental expertise following the diagnosis of diabetes in their child. The consultations were audio recorded, transcribed and analysed by one author (SN) between May 2006 and August 2007 at two university outpatient paediatric diabetes centres of excellence, one in the UK and one in the USA.[3] The study was approved by the joint Huntingdon and Peterborough/Fenland Research Ethics Committee and by the ethics boards of each institution, and was explained in detail to potential participants by the researcher prior to the consultation. Participants received recruitment packs that included an introductory letter, research information sheets, parent and health care professional consent forms and a parent questionnaire. In the USA, the privacy and disclosure form (HIPPA) was also included. Informed written consent was obtained from all participating parents, carers and diabetes health professionals prior to data collection.

Sample and design

Participants were English-speaking parents whose child, younger than six years of age, had been diagnosed with diabetes within the preceding 14 months. All parents attending the clinics and meeting the criteria for inclusion were asked to participate. The parent participants were prospectively divided into two groups to examine parents' diabetes knowledge shortly after diagnosis and near the year anniversary. The divisions were based on conversations with clinicians who noted that parents' diabetes knowledge was developing during the first four months of diagnosis and that parents had attained significant knowledge and expertise by the year anniversary. As this was an exploratory study, clinicians felt this division would provide insight into changes occurring over the first year. The two groups, *recently diagnosed* (within the first four months following diagnosis) and *experienced* (11–14 months following diagnosis), were selected in advance of consultations, based solely on the time of the child's diagnosis with no reference to parents' abilities to manage the disease. Consultations falling outside the inclusion periods were neither recorded nor analysed.

Although this study is concerned with parents' developing knowledge and expertise, it is important to note that all children attended clinic with their parent(s). Prior to the consultation the child's vital statistics were recorded by staff. During the consultation the children played with toys or drew pictures, but to the extent that was possible (based on the child's age), clinicians recognized and engaged with the child in all of the consultations.

Both clinics specialized in secondary care, so families were often seen by more than one clinician on the day of their visit thus 31 families produced the 55 consultations comprising the data set. The clinician participants included doctors, nurses, dieticians and social workers (see Tables 1 and 2). In order to maintain anonymity all participant identifiers have been excluded from the article.

In keeping with the NHS requirements, UK parents were initially introduced to the study by the clinicians[4] and were then asked to participate at their next clinic visit; one family declined. In the USA, the researcher explained the study, research packets were presented and consultation recording began immediately after informed consent had

Table 1. Characteristics of 55 consultations

By cohort and location

		N of cases	*N* of interactions	Mean age (months)	Gender	
					M	F
UK	Recently diagnosed	5	15	26	3	2
	Experienced	5	9	51	4	1
USA	Recently diagnosed	12	18	40	4	8
	Experienced	9	13	57	1	8

Table 2. Health professional interactions

By characteristics of health professionals						
		N of interactions	Dietician	Doctor	Nurse	Social worker
UK: 24 total interactions	Recently diagnosed	15	4	6	5	–
	Experienced	9	3	2	4	–
USA: 31 total interactions	Recently diagnosed	18	2	3	11	2
	Experienced	13	–	5	9	–

been obtained. All parents agreed to participate. Thirty-three consultations form the *recently diagnosed* group and 22 consultations comprise the *experienced* group.

Theoretical approach and methodology

This analysis draws on conversation analysis (CA) methodology to examine the organization of participants' (health-professional/parent) collaborative talk in the consultation. By taking an ethnomethodological approach (Garfinkel, 1967) CA treats interaction as accomplished collaboratively by those present (Sacks, 1992). In other words, within the consultation, verbal utterances are forms of social action that are both context shaped (organized in the light of the prior action) and context renewing (framing the next action) (Heritage and Atkinson, 1984; Heritage and Maynard, 2006). This form of analysis is premised on the idea that participants' social actions can be understood through an examination of their talk (Heritage and Maynard, 2006) as it is produced and managed in situ. Thus, CA aims to identify and develop understandings of what participants themselves display as meaningful, relevant and consequential in their interactions (Schegloff, 1992) without endorsing preconceived analytical hypotheses.

The consultations were audio recorded in the presence of the researcher,[5] who did not participate. Audio recording is a well-established tradition and feature of CA (Heritage and Maynard, 2006) and provides for ethnographic precision in naturally occurring data. It is possible that the presence of the researcher or the recording equipment may have influenced the nature of the interactions, however this did not appear to be borne out by the observed behaviour of the participants. It is also important to recognize that the interpretation of qualitative research may be influenced by the prior experiences of the researchers. To address this, the lead author maintained a field diary and met regularly with the other members of the research team to discuss the emerging findings and how those experiences may have influenced them. Video recording, in addition to audio data was contemplated, but clinical staff felt that this degree of distraction would upset the sensitive dynamic of the consultations.

The consultations were transcribed according to the conversation analytic conventions conceived by Jefferson (as published in Atkinson and Heritage, 1984) (see Table 3),

Table 3. Transcription conventions adapted from Heritage and Atkinson (1984)

Abbreviated key features of transcription conventions		
Sequence brackets	[	The onset of overlap
Sequence brackets	]	The point at which an utterance or utterance-part terminates
Timed intervals	(1.1)	Elapsed time in silence; 1.1 is a pause of 1 second and one-tenth of a second
Timed intervals	(.)	A tiny 'gap' within utterances
Underlining	<u>Word</u>	Indicates some form of stress, via pitch
Colon	Word::::	Indicates prolongation of the immediately prior sound Multiple colons indicate prolonged sound
Upper case	WORD	Indicates especially loud sounds
Arrows	↑↓	Indicates marked shifts into higher or lower pitch
Horizontal arrow	→	Located in the left margin point to specific parts or utterances that are discussed in the analysis

in order to convey important features of recorded talk such as word stress, pause length or intonation. For purposes of anonymity, the health professionals[6] are identified C for clinician and P for parent speakers.

Analysis

Beginning with reflective narratives of diagnosis, parents' talk during the consultations illuminates their vigilance and an emerging duality of focus. Vigilance describes watchful attention, with maximal readiness to detect and react to the child's symptoms. Although differing forms and degrees of understanding were observed among parents' responses, all parents explicated their vigilance as they related symptoms, offered candidate diagnoses or recalled their treatment decisions during the consultation. In so doing, parents demonstrated their own thought processes and levels of understanding.

The key finding was that two trains of thought regarding symptoms proceeded in parallel. One related to explanations of symptoms that postulated their existence as part of 'normal' childhood, such as common childhood illnesses or aspects of normal development, while the other related to explanations that could signify worsening diabetes. We illustrate this phenomenon by means of five examples that typify parents' progressive knowledge and confidence as they monitor and evaluate diabetes symptoms. The implementation of parallel vigilance enables parents to develop a diagnostic framework to evaluate symptoms, integrate data and make informed treatment decisions on behalf of their child.

Symptoms and the initial diagnosis

Fourteen *recently diagnosed* consultations took place within the first seven weeks after diagnosis. During these consultations, parents describe narratives of diagnosis and the physical symptoms they observed in their child as exemplified in Extract 1, which occurred during the family's second visit to clinic. They had not met the clinician previously, thus the parents were solicited to verify diagnostic information.

Extract 1: Recently diagnosed (six weeks)

1 C: And and you found out that
2 (name) had diabetes around (his/her) birthday↑
3 [is that right↑]
4 P: [Uhm::]
5 Found out shortly after, it was mid-May
6 Uhm:::
7 → (s)he was urinating frequently
8 → And was extremely thirsty
9 → And I thought (s)he had a bladder infection
10 C: Uh-huh

This fragment exhibits several important features. First, it presents the criteria the parents used to recognize their child's symptoms which ultimately led to a diagnosis of diabetes. This is accomplished through the clinician's linkage of the discovery of the disease and the temporal relationships of the child's birthday with the diagnosis of diabetes; the parent confirms both. Second, the lexical use of *found out* (L1) by the clinician, repeated in the parent's confirmation (L5), suggests the parent was unaware of the symptoms of diabetes. The parent confirms this through a narrative of discovery and the 'realisation of *How I became aware of X*' (Halkowski, 2006: 89). The parent details the child's presenting symptoms of diabetes:[7] *urinating frequently* (L7) *extremely thirsty* (L8), followed by a candidate diagnosis (Stivers, 2002), *I thought (s)he had a bladder infection* (L9). In this extract, the clinician acknowledges (*Uh-huh*, L10) both the symptoms and the parent's candidate (and incorrect) diagnosis of a bladder infection. The clinician's question is consequential as it enables parents' recall and links their observation to the ultimate diagnosis.

Extract 1 appears to mark a point at which the parent's life experiences are no longer adequate to understand what is happening to the child. The parents' diagnostic vocabulary references a primary care medical problem rather than a symptom of a chronic disease. This parent has not begun to display parallel vigilance, but the recognition and evaluation of symptoms may well begin its development.

Symptoms and under-developed parallel vigilance

As families move beyond the initial diagnosis, our data indicate parents' concerns reference symptoms of 'normal' childhood illnesses juxtaposed with symptoms potentially responsible for glucose (in)stability. A further 19 *recently diagnosed* consultations are represented by Extract 2 and demonstrate under-developed parallel vigilance as parents attempt to align symptoms with limited diabetes knowledge and experience. The ‘a’ represents the clinician’s open-ended solicitation, ‘b’, the parent’s observations.

Extract 2: Recently diagnosed (six weeks)

1	C:	a→	how’s everything goin’↑
2	P:		Good, good.
3		b→	Last night (child) actually threw up last night
4	C:		Okay
5	P:		But I don’t think it was just
6			(.)
7			(child’s) been complaining of a
8		b→	a sore throat that I think is
9			(1)
10		b→	Phlegm
11			(.)
12	C:		Okay
13	P:	b→	But this morning sugar was re::lly high
14		b→	And I don’t know if it’s from that last night
15	C:		Okay.

The clinician solicits the parent with an open-ended question, *how’s everything goin*↑ (L1). ‘Things’ as Frankel (2001) suggests, works to enable parents to identify any aspect of management, treatment or life-style observation. In this example, *everything* provides for filling in evolving informational gaps that occurred outside the consultation, as well as exploring the parents’ doubt of their own diagnostic observations.

The parent initially responds socially (Robinson, 2006; Sacks, 1975) with *Good, good* (L2), but repairs and begins to qualify an appraisal of the child’s health with *actually* (L3). Although the parent orients to three confusing symptoms, *threw up* (L3), *a sore throat* (L8) and *Phlegm* (L10), (s)he avoids explicit diagnosis and appears to speculate that the cause (Gill, 1998), (*threw up*) was phlegm. As the parent defers to uncertainty and possibly the clinician’s expertise, *But I don’t think* (L5), (s)he states a parallel observation and the need for further clarification, *sugar was* re::*ally high* (L13), *And I don’t know if it’s from that last night* (L14).

Extract 2 is an example of how parents begin to categorize symptoms as possibly diabetes-related or not. First, this parent evaluated the sore throat and related vomiting of phlegm. In parallel however, the parent recognizes a component of the disease … *sugar was* re::*ally high* (L13) and illustrates ‘under-developed’ parallel vigilance. This parent’s challenge is stated in the comment … *if it’s from that* … (L14). How these elements fit together may be difficult to determine initially, however parents do search to reduce uncertainty and to comprehend all the aspects of the disease. Under-developed parallel vigilance is characterized by the effort to differentiate two parallel strands of medical information that may be related and require treatment or may be merely coincidental.

Finding a balance – developing parallel vigilance

Our data suggest that increasingly, parents weigh their management options and initiate regime changes based on testing results and observations independent of diabetes clinicians. For these parents, the process of observing symptoms and proposing candidate diagnoses involves implementation of increasing knowledge and an experiential-driven form of parallel vigilance. It is more rational and thoughtful as parents seek to find a better balance between the normal aspects and the diabetes aspects of their child's life, as they continue to watch and respond to both in parallel.

The family in Extract 3 is representative of *experienced* parents who routinely focus on their child's glucose data, their child's symptoms and glucose responses, and the steps they take to improve health. This parent describes uncontrolled fluctuations in glucose as a result of travel and exercise, but assesses the symptom of a *croaky throat* (L49) in the context of parallel vigilance.

Extract 3: Experienced (11.5 months)

1	C:	An how'r yur blood sugars lookin'↑
2	P:	Uhm::: yeah we started
3		(2.0)
4		we were
5		(2.0)
6	→	when we came back from the [holiday]
7–14		(talk about changes in insulin doses)
15	P:	we were gettin' loads [of]
16	C:	[Yeah]
17	P:	lows and hypos
18–22		(further description of hypoglycaemia)
23	P:	and and then we had things like last week
24	→	we had sports day which threw everything
25–48		(Talk about races and sports)
49	P: →	(s)he's got a bit of a croaky throat [now]
50	C:	[yeah]
51	P:	So again I don'
52		(2.0)
53		whether we're thrown in a high or
54		(s)he's comin' down with something
55		(3.0)
56		uhm I'll remain optimistic and it's actually nothing at all↑

The clinician's solicitation, *An how'r yur blood sugars lookin'*↑(L1), continues the consultation agenda, specifying blood sugar data and enabling the parent to provide a perspective on the many decisions that parents must make. Interestingly, the clinician specifies '*yur*' blood sugars indicating that although the blood sugar reactions are the child's, '*yur*' implies the collective responsibility and ownership of problem-solving belongs to the parents' management. This parent responds with 'we' as each activity and its physiological impact on the child's reactions is detailed. Referencing the collaborative efforts required to manage the child's several disturbing episodes and poor glucose control, the parent attempts to put the glucose values in perspective. After a number of false starts, *Uhm::: yeah we started (2.0) we were (2.0)* (L2–5), the parent hints at either the large amount of information required to understand all that has happened or the difficulty in organizing it in a coherent way (Goodwin, 1981). The three events – a holiday trip, a school sports day and a possible illness – are unrelated to the others, yet each shares an association with fluctuating glucose values that need to be evaluated. In parts of the transcriptions not shown here (L7–14, 18–22, 25–48), the parent details the active decisions that did not resolve the child's poor glucose control. With a further tentative candidate diagnosis about a *croaky throat* (L49), the parent reminds us of how difficult the management of diabetes can be. (S)he appears to defer to the clinician's expert status and the effort to attain glucose control adding, *so again I don'* (L51) and without finishing the thought, concludes with three alternatives: *we're thrown in a high* (L53), *comin' down with something* (L54) or *it's actually nothing at all*↑ (L56).

As the parent weighs the potential diagnostic alternatives of a *croaky throat* (L49) within developing parallel vigilance, this parent is alert to a struggle with two separate but always competing tensions: (1) are the child's inconsistent glucose values due to inadequate management leading to worsening diabetes; or (2) are they due to other factors that are out of one's control? Silverman (1987) reminds us that the weight of parent [patient] responsibility as 'active decision-maker [is] … at the cost of being morally responsible for actions' (1987: 213).

…how'r yur blood sugars lookin'↑ (L1) provides an important perspective on the many decisions impacting parents' diabetes management. It is apparent that this parent is fluent in the language and mechanics of the diabetes regime. However, in light of the child's unstable glucose responses, the hesitations at the beginning of the narrative (L2,3,5) and the two lengthy pauses towards the conclusion (L52,55) may indicate this concern.[8] This dilemma, to define causality and implement decisions to improve outcomes, is at the core of parent care and parallel vigilance.

The dual focus of parallel vigilance: is it diabetes or is it normal?

Extracts 4 and 5 illustrate how two families exhibit the dual focus of parallel vigilance. Extract 4 is representative of three atypical *recently diagnosed* consultations in which a parent had been diagnosed with Type 1 or Type 2 diabetes. This consultation illustrates how parallel vigilance can precede the diagnosis of diabetes and is important because these parents' prior experiences with diabetes accelerate and heighten the implementation of parallel vigilance for their child.

Extract 4: Recently diagnosed (17 days)

1 C: So:::you guys are new to the clinic, [right↑]
2 P: [uh-hm::]
3 C: You've never been here before=

4 =so the first thing we like to talk about is
5 what was (child’s) diagnosis like and when was that
6 P: ·Uhm::: ·
7 It was almost three weeks ago.
8 C: Uh-hm:::
9 P: We
10 (.)
11 uh
12 (.)
13 we’re
14 (.)
15 (Parent’s name) had ja-juvenile diabetes
16 [since]
17 C: [uh-huh:::]
18 P: (s)he was 10 so we’ve been looking for signs in our kids
19 since they were born.
20 (s)he’s a twin. And ah:::
21 (.)
22 C: [oh-kay:::]

The opening sequence of this consultation provides the parents an opportunity to focus on their child’s diagnosis. The clinician solicits the parents with a two-part closed-ended question. The first part defines the temporal condition of the consultation, *new to the clinic*, (L1) and the second part, *[right↑]* requests confirmation from the parents. With agreement, the clinician continues to set the agenda, *what was (child’s) diagnosis like and when was that* (L5). The parent responds and approximates the time of diagnosis (*almost three weeks ago* (L7)) but does not address the clinician’s request about the circumstances of diagnosis. Rather, information is volunteered that more overtly attends to a different agenda, one in which ‘the patient’s “lifeworld” is leaked in ways that are subordinate to the agenda of the question’ (Stivers and Heritage, 2001: 167). The parent states *(Parent’s name) had ja-juvenile diabetes [since] (s)he was 10* (L15,16,18) and affirms their rational account and that their experience with the disease is long-standing. Thus, as a result of the parents’ lived reality, they’ve *been looking for signs in our kids since they were born* (L18–19). Their vigilance has been constant and parallel, alert to any symptom of illness that may confirm their worry and their child’s diagnosis of diabetes. Although this family is among the recently diagnosed, their understanding of diagnostic features of *signs* appears to suggest their surveillance will continue, as the parent adds, (*s)he’s a twin* (L20). This shift from *what was (child’s) diagnosis like* (L5), acknowledges another perspective of parallel vigilance for this family; now that one child has been diagnosed, the parents will be even more vigilant for symptoms of diabetes in the twin (Soltesz, 2003).

Extract 5 is an exemplar of the phenomenon of parallel vigilance. It is from a routine diabetes clinic visit that occurred 11 months after the initial diagnosis. Four sequences are bolded to highlight these parents’ implementation of their parallel vigilance. They detail their recognition of a potential problem, their response to their child’s symptoms and the steps they take to manage the episode and avert uncertainty. We join the consultation as the clinician asks about the child's and parents' experiences with hypoglycaemia.

Extract 5: Experienced (11 months)

1	C:	And (child) hasn't had a serious low sugar?
2		(.)
3		Where (s)he actually passed out?
4		(.)
5		or anything?
6	P:	***No***
7		***I think once (s)he was taking a nap***
8		***and I thought (s)he was passin' out***
9	P:	***So we're testin'***
10		***(S)he falls asleep in the car***
11		***We get nervous***
12	C:	Well::: actually I mean that's actually
13		One of the signs of low
14		But really tired sleeping ya know [uh-m:::]
15	P:	[We know]
16	C:	[Uhm::]
17	P:	[Well]
18		(S)he had slept over her aunt's house
19		And of course a sleepover party
20		you know you're tired and then (s)he swam all day
21		I pick her up at 4
22		Travel 20 minutes home
23	P:	***I look (s)he's asleep in the back***
24		***"Is it a sleep or is (s)he having a low?"***
25		***I erred [on the side]***
26	C:	[you check]
27	P:	***Of caution***
28		***pulled over woke***
29	C:	[check]
30	P:	***[(child) up]***
31	P:	***Give (child) a juice box and said***
32		***"okay, now you can go back to sleep"***

Without mentioning the medical term hypoglycaemia, the clinician solicits the parents' literacy based on their child's glucose reactions. Thus, parent management of 'low sugar' is framed within two related contexts, *serious* (L1) and *passed out* (L3). In response, the parent confirms *No* (L6) indicating the child had not experienced these symptoms, but continues to narrate the tension at the core of parent-managed medical treatment and the uncertainty highlighting their implementation of parallel vigilance, *I think once (s)he was taking a nap and I thought (s)he was passin' out* (L7–8).

This first response illustrates how everything about the child must be evaluated from two different perspectives – that of a child without a chronic disease (L7) and that of a child with diabetes (L8). Thus, a tired child taking a nap does not produce contentment in these parents, but rather triggers worry that the child may be unconscious from very low blood sugar.

The parent reinforces the uneasiness with the situation, *so we're testin', (S)he falls asleep in the car* (L9,10), *we get nervous* (L11), and indicates that they had tested the child's blood glucose before (s)he fell asleep. In this way they are using their more recent life experiences (learning to measure blood glucose) to minimize the complexity. Nonetheless, they do not trust their own test or judgment – *we get nervous*. The parent summarizes the circumstances leading up to a child's normal reaction to a sleep-over/swim party (L18–20), but states plainly the parallel context and their dilemma, *"Is it a sleep or is (s)he having a low?"* (L24). Even though they should be reassured because a nap for a young and tired child is normal and the blood test did not indicate a *low blood sugar* (L9), in parallel they continue to be vigilant that the nap could be a serious manifestation of diabetes. Rational vigilance (tired child, nap, normal blood glucose) can be over-ridden by an anxious vigilance, *we get nervous* (L11), in the face of the profound negative consequences of hypoglycaemia.

The parents describe how they resolved their dilemma, *I erred [on the side] Of caution, pulled over woke [(child)] up, Give (child) a juice box and said, "okay, now you can go back to sleep"* (L25, 27–28, 30–32). So in spite of their own common sense that the child is napping and their own blood test indicating (s)he does not have low blood sugar, they act on the small possibility that the nap indicates low blood sugar; they wake the child and give him/her juice to increase the blood sugar. They demonstrate parallel vigilance as an ongoing process, of evaluating their child's symptoms and data against the fear of a serious consequence of diabetes, which in this case led to cautious and pragmatic actions – *erred [on the side] Of caution* (L25, 27).

Discussion

Recent studies examining parent-management of their child's diabetes have used self-reporting scales, interviews and/or questionnaires to assess parental stress, coping and the psychosocial adjustment to diabetes (Grey, 2009; Smaldone and Ritholz, 2011; Streisand et al., 2008). These studies have led to the development of programmes designed to address some of these issues (Jonsson et al., 2010; Rearick et al., 2011; Sullivan-Bolyai et al., 2011, 2012). However, the interactions between clinicians and parents of very young children with diabetes, through which collaborative partnerships are constituted and parental expertise is enabled and promoted, have not been studied. By examining parents' talk during the consultation as they describe their child's disease and their solutions to episodes of ill health and uncertainty, this study begins to address those interactions.

Based on the study reported here, we propose the new concept of parallel vigilance, a duality of focus that combines the normal watchfulness exhibited by all parents as they protect their children, with an additional intense, parallel watchfulness for signs of potentially serious manifestations of diabetes. The concept was derived from an analysis of parents' reports of caring for a child with diabetes as they use their previous life experiences to assess their child's health through a dual process that looks backward, at symptoms of childhood illnesses already known to parents, and forward, at the as yet unknown symptoms of diabetes. Thus, parents' orientations draw on normative understandings of previously known conditions contrasted with the uncertainties and unknowns of diabetes. This results in parallel vigilance, a diagnostic tool that supports parents' symptom based decision making.

Self-care relies on an embodied, practical knowledge that is something you do, not something you acquire (Pickard and Rogers, 2012). In the consultation, parents describe that a considerable part of what they do is parallel vigilance. As they attempt to create order (Kralik et al., 2004) by evaluating symptoms in their child, they utilize parallel vigilance, a feature of parental decision making and developing expertise and a consistent element of the chronic illness experience for parents with a child with diabetes. Lippa et al. (2008) have shown that problem detection skills and effective problem solving strategies correlate with better adherence and greater glycaemic control. As parents evaluate symptoms, parallel vigilance is a mechanism for both problem detection and problem solving strategies, which may lead to better outcomes for the child.

Our data suggest that the disruption of everyday structures requires parents to ask 'what is going on here' (Bury, 1982: 169) as their former commonsense and experienced routines are brought into consciousness but are no longer sufficient to maintain their child's health. Following diagnosis, 'under-developed' parallel vigilance becomes a necessary feature of symptom analysis as parents' medical experience does not extend beyond the parameters of 'being a reasonable observer of [their child's] health' (Halkowski, 2006: 107). A more developed form of parallel vigilance evolves as parents gain knowledge and experience to identify and interpret symptoms. By the first anniversary of diagnosis, parents use parallel vigilance to assess their child's symptoms independently and with increased confidence as they consolidate their judgements into treatment decisions. They appear to examine the possible causes of symptoms in a process related to the differential diagnosis used by clinicians (Mark and Wong, 2012). What in other circumstances might be considered normal or a routine illness becomes a focus for three questions: (1) Are the symptoms related to diabetes? (2) Are the symptoms exacerbated by abnormal glucose values or vice-versa? (3) In either case, how should each be treated? As parents ask these questions they employ the dual focus of parallel vigilance as an active and iterative process. This comprehensive approach is consistent with Candlin's (2002) steps towards developing expert knowledge and coherent understanding. It is also consistent with previous research by Peräkylä (2002), who argues that patients [parents], like doctors, have strategies through which candidate reasoning emerges. He demonstrated patients' displays of expert behaviour and diagnostic reasoning through their extended responses. In our study, we see similar displays through the extended responses of parents during the consultations.

It is important to recognize the limitations of this study. While the data presented here are drawn from consultations within the first 14 months following diagnosis, they are composed of defined encounters within the first and last four-month periods and do not capture the ways in which these encounters relate to one another. In addition, it is important to understand whether parents in a non-academic, primary care setting describe parallel vigilance. To examine both of these limitations, a follow-up study with primary and secondary care sites and a larger enrolment of *recently diagnosed* families followed longitudinally should be undertaken. This would increase understanding of both the generalizability of parallel vigilance and its development over time, although the fact that the same findings were obtained in settings in two different health systems does support the probability that these findings are generalizable more widely. The influence of parents' socio-economic status on doctor–patient interactions, the development of lay expertise or the explication of parallel vigilance was beyond the scope of the current article, however that influence would also be worthy of further study.

Current guidelines detail the management and care of young children diagnosed with diabetes (ADA, 2005; DoH, 2001b, 2007; Swift, 2009), however, they do not provide for an understanding of how clinicians help parents redirect their experiences with uncertainty into a trajectory of knowledge and expertise. The observations in this article suggest that parents' talk enacts a growing confidence in management of their child's disease in the face of questioning from professionals. As clinicians discuss features of the diabetes regime, they create an opportunity for parents to articulate their 'diagnostic' understanding through explication of parallel vigilance. Thus, the concept of parallel vigilance is relevant both to the patient (parent) experience and to communication within the clinical encounter: (1) as a measure of parents' developing knowledge and expertise; (2) as an enabler of parental contribution to the consultation; and (3) as a lens into parents' management and decision-making processes and skills. The article contributes to an understanding of how studies of consultations involving parents of children with other chronic diseases such as asthma, rheumatoid arthritis, sickle cell disorder, cancer and others could not only illuminate consultation interactions, but may give insight into how those parents conceptualize and manage those diseases.

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Notes

1 Hereafter, Type 1 diabetes mellitus currently abbreviated, T1D, will be referred to as *diabetes*.

2 The limitations Prior (2003) considers are based on the concept of lay expertise, specifically as 'layman' and 'expert' are defined in the *Oxford English Dictionary*. He concludes that lay people with experiences of their illness and disease are not 'skilled and practiced in the diagnosis and management of illness' (2003: 53).

3 Initially we wanted to investigate whether there were any systematic differences between the two countries as this would inform our judgement about the generalizability of our findings. However, if any differences existed they were too subtle to detect, therefore this aspect of study was not developed. It is noteworthy that the same features emerged in two clinics operating in different health systems and cultures of clinician–patient relationship.

4 While the researcher waited for the Honorary Contract and 'Enhanced Background Check' from the Criminal Records Bureau (CRB) the clinicians introduced the study to participants.

5 If scheduling conflicts prevented the researcher being in the clinic, the attending clinician assisted in tape recording the consultation. Data were downloaded onto a password protected

computer and secured in a locked facility. The digital recorder was also kept in a locked and secured location.

6 Although the overall focus of the consultations reflected the specializations of the clinicians, further identification of the clinicians would compromise confidentiality. Solicitations from the clinicians, however, often elicited a response from the parents that explicated parallel-vigilance.

7 All of the 33 recently diagnosed families narrated their child's presenting symptoms. Questions that specifically requested pre-diagnostic symptoms were absent from the experienced consultations, unless the family were new to the programme or the clinician had not met the family earlier. This occurred twice in our data.

8 Delays or restarts within a turn suggest a dispreferred action where the difficulty to produce a response is forthcoming; worry or concern could be a reason for that difficulty. See Heritage (1994); Stivers (2005a, 2005b).

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