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Peering into a Chilean Black Box: Parental Storytelling in Pediatric Genetic Counseling

Jessica Ordonez · Sonia Margarit · Katy Downs · Beverly M. Yashar

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Abstract While genetic counseling has expanded to multiple international settings, research about providing culturally sensitive services to non-U.S. patients is limited. To gain insights, we utilized a process study to explore parental communication in pediatric genetics clinics in Chile. We utilized a phenomenological hermeneutic approach to assess storytelling in six pediatric sessions that were conducted in Spanish, and translated into English. The majority of the sessions focused on information gathering (35 %), and providing medical (20 %) and genetics education (18 %). The 14 instances of storytelling we identified usually emerged during information gathering, genetics education, and the closing of the session. Stories illustrated parental efforts to create a cognitive and emotional context for their child's genetic diagnosis. Parents emerged as competent caregivers who discussed the role of the child as a social being in the family and the larger community. Our analysis found that genetic counseling sessions in the U.S. and Chile are structured similarly and although communication is not a balanced process, parents use storytelling to participate as active agents in the session. Via storytelling, we learned that parents are working to understand and gain control over their child's genetic diagnosis by relying on mechanisms that extend beyond the genetics appointment.

Keywords Storytelling · Pediatric · Communication

Introduction

Since its formal inception in 1971 in the United States, genetic counseling has expanded to multiple international settings spanning five continents (Transnational Alliance for Genetic Counseling [TAGC] 2012). At present, there are no formal genetic counseling programs in South America and physicians with clinical training in genetics are the main providers of genetic counseling. In Chile genetic services are localized to metropolitan regions and are provided by one US-trained ABGC-certified genetic counselor and 27 clinical geneticists (Margarit et al. 2013). In countries without established genetic counseling models, there has been increased awareness of the importance of providing genetic counseling to patients and family members at increased risk of hereditary disorders (Margarit et al. 2013; WHO 2006). A report from UNESCO in 1995 surveyed medical specialists from the United States, United Kingdom, Italy, Chile, Mexico, Japan, Israel, China, and Zaire on their definitions of genetic counseling. In this report, a Chilean geneticist described genetic counseling as: "a medical process of communication between a physician and a consultant (counselee) where scientific knowledge, data and facts are exchanged in order to provide a framework to understand the genetic problem of the patient and the family" (Revel 1995).

While multiple related but distinct definitions of genetic counseling have emerged across the globe in the last 41 years, there is a clear information gap on the reality of clinical practice outside of the United States. The existence of distinct ethical, legal and social frameworks around the world

J. Ordonez (✉)
John T. Macdonald Foundation Department of Genetics,
John P. Hussman Institute for Human Genomics,
University of Miami Miller School of Medicine,
1501 NW 10th Ave; BRB 334 (M-860), Miami, FL 33136, USA
e-mail: jordonez@med.miami.edu

S. Margarit
Medical School, Clinical Alemana- Universidad del Desarrollo,
Av. Las Condes 12.438 Lo Barnechea, Santiago, Chile

K. Downs
Undergraduate Research Opportunity Program,
University of Michigan, 1190 Undergraduate Science Building,
Ann Arbor, MI 48109-2215, USA

B. M. Yashar
Department of Human Genetics, University of Michigan, 4909
Buhl, 1241 E. Catherine Street, Ann Arbor, MI 48109-5618, USA

impact multiple aspects of the genetic counseling interaction, including the expectations from healthcare providers regarding the provider-patient relationship, available options for medical intervention, as well as the process of decision-making and health beliefs. These variations highlight the importance of tailoring genetic counseling so that it is responsive to the sociocultural background of the individual as opposed to assuming that there will be a universal approach that will fit all cultures (Edwards 2010; Pour-Jafari and Pourjafari 2010; WHO 2006).

Process studies of genetic counseling can be a useful tool in unveiling the real-time nature of counseling in international settings. Different from studies that focus on outcome variables of genetic counseling (i.e. uptake of genetic testing, client satisfaction, and behavior change), process studies investigate the content, behaviors, and relationships that constitute the genetic counseling interaction (Biesecker and Peters 2001; Meiser et al. 2008; Ong et al. 1995). Communication research, one type of process study, uses language to investigate the ways in which information is conveyed by genetic counselors and understood by clients (Ellington et al. 2005, 2006; Kessler 1981; Roter et al 1988; Wang et al. 2004). Although there have been studies that have used this tool to focus on the role of genetic counselors, few communication studies of genetic counseling have focused on the role of patients (Babul-Hirji et al. 2010; Benkendorf et al. 2001; Meiser et al. 2008; Smets et al. 2007). Parental communication studies in countries without established genetic counseling models will provide information about clients' existing needs and goals for the genetic counseling process, information which can help formulate culturally-sensitive counseling models.

There are a variety of approaches that can be used to apply communication research to understand the thoughts and feelings of a patient during a medical encounter. Storytelling (which focuses on the communication of ideas and thoughts through the exploration of past and future experiences) is particularly well suited to studies on the practice of genetic counseling because it is sensitive to the process by which individuals interact and allows the researcher to utilize past and/or future experiences to compare and understand different states of being (Carolan 2005; Cordella 2004a, b). Stories can be about characters, relationships, plots, places and events: Their power is due to the fact that they reflect people's personal, contextually-grounded understanding of their experiences and how they relate to health and/or illness (Anderson 1998; Mishler et al. 1989).

Although storytelling has received increased attention in genetic counseling, particularly in cancer genetics (Larkey and Gonzalez 2007; Larkey et al. 2009), storytelling has yet to be explored in a pediatric setting outside the United States. Genetic counseling interactions in Chile may be amenable to the study of storytelling. The linguist Marissa Cordella has performed extensive work on the communication process in Chilean medical consultations and found that patients frequently use storytelling in adult, outpatient clinical settings. Storytelling is a "voice" or communication pattern that has a functional relationship with the doctors' speech and provides a niche for empathy, respect, genuineness, unconditional regard and partnership (Brock 1995; Cordella 2004a, b; Smets et al. 2007).

The primary goal of this study was to explore parental communication and identify common themes during pediatric genetic counseling sessions in Chile. Using the perspective that storytelling could help uncover these themes; we audiotaped genetic counseling interactions and utilized a qualitative perspective to decode the structure of counseling sessions. Our analysis found similarities to the US-based model of health care, explored the communication patterns between the health care providers/geneticists and parents and identified ways in which parents are actively engaged in genetic counseling.

Methods

Data Collection

Data was collected from the Pediatric Genetics Clinic at *Hospital Padre Alberto Hurtado (HPH)*, in Santiago, Chile. *HPH* is a public, metropolitan hospital serving close to 450,000 individuals in a low socioeconomic status area of Santiago, where most community members have limited access to secondary and post-secondary education. Spanish is Chile's national language; health providers and individuals seeking care at *HPH*, are native Spanish-speakers. The research protocol and informed consent documents were approved by the Interhospital Ethics and Research Review Board (Santiago, Chile) and the University of Michigan Medical Institution Review Board (IRBMED: HUM00041580).

The schedule at the pediatric genetics clinic was previewed from June 10 to June 22, 2010 to identify cases with a suspected or established genetic diagnosis. Sixteen parents of patients meeting these criteria were invited to participate. Three parents declined enrollment, one parent/family failed to meet inclusion criteria, and twelve parents were enrolled as participants. Parents of children with a suspected or established genetic diagnosis who were younger than 18 years of age; had an established genetic diagnosis themselves prior to the visit; were deaf, pregnant or not fluent in Spanish were excluded from the study.

Two medical geneticists, who agreed to participate as subjects in this research study, provided genetic counseling in the *HPH* pediatric genetics clinic. One provider completed pediatric genetics training in a Chilean tertiary care center while the second provider was US-trained and credentialed by the American Board of Medical Genetics. It is unknown whether the geneticist was already familiar with the child's

parents prior to the visit or the date when the relationship was initially established.

Following provision of informed consent for parents and health providers, twelve genetic counseling sessions were audiotaped from beginning to end. The tapes were screened for optimal audio quality (this resulted in the exclusion of 2 tapes) and data about audiotape length was obtained at that point in time. The audiotapes were transcribed in their entirety into written Spanish. Transcription conventions were adapted from the linguistic literature (Du Bois 1991; Cordella 2004a, b; Jefferson 2004) to account for conversation overlap, silence, meta-transcription, voice quality, tone, Chilean colloquialisms and specific word shortening or lengthening patterns in Chilean discourse (Table 1).

Ten transcripts were translated into written English by the primary author, a native Spanish speaker, all identifiers were removed from the translated transcripts and three of the four authors (JO, KD, BMY) independently screened the transcripts for the presence of storytelling. Storytelling was operationally defined as a prompted or unprompted account by which parents explore past or future experiences and reflect on a present state of being by the use of narrative. In order to ensure that the application of this definition was equivalent for all coders, the three coders jointly evaluated one transcript through an iterative process in which definitions of storytelling in the literature were grounded to the transcript body. After consensus was reached on the operational definition and the storytelling identification process, the three coders independently screened the remaining nine transcripts to identify instances of storytelling. Six of the nine transcripts contained instances of storytelling and were selected for analysis.

Coding

Three coders/authors coded six transcripts with NVivo 9.0 software using a phenomenological hermeneutic approach. This is a method of structured reading and interpretation well known in philosophy, by which different reading levels are used to build bridges between the reader and the text; the text and its producers; and the social context (Krippendorff 2004; Schiffrin et al. 2001). Each transcript was coded three times to reflect three levels of reading.

The first reading level mapped each of the six genetic counseling sessions into seven components (Walker 2009). The scheme described in Table 2 was adapted from outpatient medical communication studies by Cordella 2004a, b and genetic counseling communication studies by Babul-Hirji et al. 2010. Each session was coded to reflect an opening, information-gathering section, medical and genetics education, psychosocial counseling and closing (Table 2). The speech of the healthcare providers was used to identify the start and finish of each of these components. The primary author coded the first reading level in five transcripts after all coders reached consensus on the identification process for session components in one transcript. The amount of text comprising each component of the session, which included both healthcare provider and parental dialogue, was measured as the total word-count of individual session components (i.e., opening, information gathering, medical or genetics education,

Table 1 Transcription convention system (Adapted from Du Bois, Cordella and Jefferson) (Du Bois 1991; Cordella 2004a, b; Jefferson 2004)

Type of verbal pattern	Meaning	Symbol
Sequence	Overlap: health provider	[word]
	Overlap: parent	[[word]]
Meta-transcription	Comment	((word))
	Unintelligible	XX
	Uncertain	**
Voice quality	Emphasis	CAPITAL LETTERS
	Laugh quality	<@word@>
	Whisper	<PwordP>
Transitional continuity	Appeal	?
	Exclamation	!!
	Continuing	,
Pause	Long pause	…… (N)
	Medium pause	…
	Short pause	..
Disfluency	Truncated word	Wor-
	Colloquialism in Spanish	©
	Spanish truncated syllable in para (pa') and pues (po')	‘
Lengthening	Vowel lengthening	:

Sequence Linearity of speech and overlap

Meta-transcription Assessment about the transcription process

Voice quality Speech that is louder than surrounding speech, laughter or whispering

Transitional continuity Boundaries and closure of speech

Pause Break of sound between successive talk

Disfluency Interruptions or irregularities of speech

Lengthening Extension of the length of time in the articulation of a sound

Table 2 Genetic counseling session components (Adapted from Babul-Hirji and Cordella) (Babul-Hirji et al. 2010; Cordella 2004b)

Session component	Relevant content
Opening	Greetings, introductions, agenda setting and initial exploration
Information gathering	Family and medical history intake
Education - medical	Medical management, prognosis, natural history
Education - genetics	Genes and chromosomes, inheritance, recurrence risks
Psychosocial counseling	Identification of familial and community support groups/networks, exploration of coping mechanisms & decision-making, adaptation to illness
Physical exam	Body inspection, palpation, percussion, and auscultation
Closing	Session summary and follow up plan

etc.) and expressed as a percentage of the total word-count in the transcript. We used Excel version 12.2.4 to estimate the average percent text coded for every genetic counseling session component across transcripts.

Verbal dominance was also assessed in each transcript by calculating the total word count attributed to either the healthcare provider or the parent and expressing this as a percentage of the total word count in the transcript. We used Excel version 12.2.4 to estimate the average verbal dominance for parents and healthcare providers across transcripts. Portions of the session in which there was silence, when the healthcare provider exited the room, parental or healthcare provider playful interaction with the child; or when the parent and child left the room for the child to be measured and weighed were coded as "other". Since our transcription system allowed us to capture pauses of different length, we were able to reflect silence present in the tapes as part of our coded text.

In the second reading level, the stories were mapped to the structure of the genetic counseling session that had been defined in the first reading level. Each story was analyzed quantitatively by calculating verbal dominance; this was defined as the percent text in a given story attributed to either the healthcare provider or the parent. The verbal dominance during storytelling was averaged for all stories and compared to the average verbal dominance for all transcripts obtained from the first reading level. The last phase of analysis (the third reading level) combined content analysis of storytelling with the structural analysis of text in the first and second reading levels. The three authors independently coded all stories to identify themes and subthemes of storytelling and then met as a group to reach consensus. This approach resulted in an interpretation of the text as a whole and created a comprehensive understanding of parental communication.

Results

Demographics

The parents involved in the six sessions were all female with an average age of 30 years (Table 3). Most of the pediatric patients

Table 3 Genetic counseling session details

Session	Audiotape length (min' sec")	Parental age (yr.)	Sex of child	Child age (yr.)	Diagnosis	NP/RV
#1	30' 19"	36	F	10 .8	Down Syndrome (Translocation)	RV
#2	27' 39"	25	F	5	Aicardi Syndrome*	RV
#3	23' 36"	36	F	1.4	Down Syndrome	RV
#4	34' 43"	29	M	10	Bilateral CL/P, Panhypopituitarism	RV
#5	35' 59"	22	M	0.6	Hypochondroplasia	RV
#6	22' 53"	32	F	0.3	Down Syndrome	RV
Average	~29'	~30	4/6 F	~5		

CL/P Cleft lip and palate
NP New patient
RV Return visit
(*) Working diagnosis
M Male
F Female

were also females with an average age of 5 years. All families had previously been evaluated in the genetics clinic. Three sessions involved chromosomal diagnoses (Down syndrome), and three sessions involved established or working diagnosis of single-gene conditions. On average, the genetic counseling sessions were 29 min in length, ranging from~23 to 36 min.

First Reading Level: Mapping the Session Structure

Each transcript was coded for the presence of the seven components of a genetic counseling session (Table 2). Four of the seven components (opening, education-medical, information gathering and closing) were identified in all transcripts. Parental and healthcare provider dialogue related to the physical exam occurred in five of the six sessions; genetics education occurred in four sessions and psychosocial counseling occurred in one session.

Among the transcripts there was a wide range in the percent text coded for each component of the genetic counseling session (Table 4). On average most conversation occurred during information gathering (~35 %), the discussion of medical information (20 %) and genetics education (~18 %). Opening, closing, and the physical examination comprised ~25 % of coded text; psychosocial counseling occurred only one time and accounted for an average of <2 % coded text.

In order to determine if the logistics of the session made it possible for parents to function as active agents, we analyzed verbal dominance in each transcript (Fig. 1). On average, we found that there were opportunities for parental dialogue. While the healthcare providers were the primary communicators in the sessions (54.2 % of coded verbal communication), approximately one-fourth of the conversation in these sessions was contributed by the parent (26.9 %). The remaining text (18.9 %) was coded as "Other" and represented instances of silence or absence of the healthcare provider and/or the parent as described in the Methods sections. There was a wide range in percent text coded for verbal dominance across transcripts (Parental talk: 20.52 %–33.12 %; Healthcare provider talk: 46.6 %–66.9 %; Other: 12.5 %–25.7 %).

Second Reading Level: Storytelling

Since parents seemed to be active participants in the genetic counseling session, we explored their role as storytellers. A total of 14 stories were identified in the 6 transcripts and comprised on average 8 % of coded text with a range of 2.3 %–14.3 %. The number of stories/transcript ranged from 1 to 4 with an average of 2.3 stories/transcript. Transcript #1 had 4 stories, representing 14 % of coded text. Transcripts #4 and #5 had three stories each, comprising 13 % and 4 % of coded text. Transcript #6 had two stories with 6 % of coded text as storytelling. Finally, storytelling comprised 2 % and 6 % of coded text in Transcript #2 and #3, each with one story.

Using the genetic counseling map created in the first reading level, we found that most stories developed during information-gathering (42.8 %; 6 of 14 stories), while some developed during genetics education (28.6 %; 4 of 14 stories). The remaining ~25 % of stories developed during medical education, physical examination and closing; there was no storytelling during psychosocial counseling. Although most stories developed entirely during one component of the genetic counseling session (e.g. information gathering), other stories developed over more than one component of the session (e.g. information gathering and medical education).

Table 4 Mapping the genetic counseling session structure

Transcript	OPN	IG	PE	MED	GE	COUNS	CL
#1	2.2 %	12.9 %	–	11.4 %	64.9 %	–	8.3 %
#2	1.5 %	38.3 %	3.3 %	28.0 %	10.3 %	9.1 %	8.1 %
#3	1.5 %	48.7 %	11.4 %	26.3 %	–	–	10.8 %
#4	2.4 %	47.9 %	9.6 %	6.3 %	27.2 %	–	6.0 %
#5	6.9 %	37.6 %	17.7 %	20.4 %	3.4 %	–	13.2 %
#6	3.7 %	23.2 %	24.1 %	27.8 %	–	–	20.1 %
Average	3.0 %	34.8 %	11.0 %	20.0 %	17.7 %	1.5 %	11.2 %

% Word count of each session component relative to transcript word count

OPN Opening

IG Information-gathering

PE Physical exam

MED Medical information-delivery

GE Genetics education

COUNS Psychosocial counseling

CL Closing

Average percent text coded for a given session component in each transcript divided by the number of transcripts

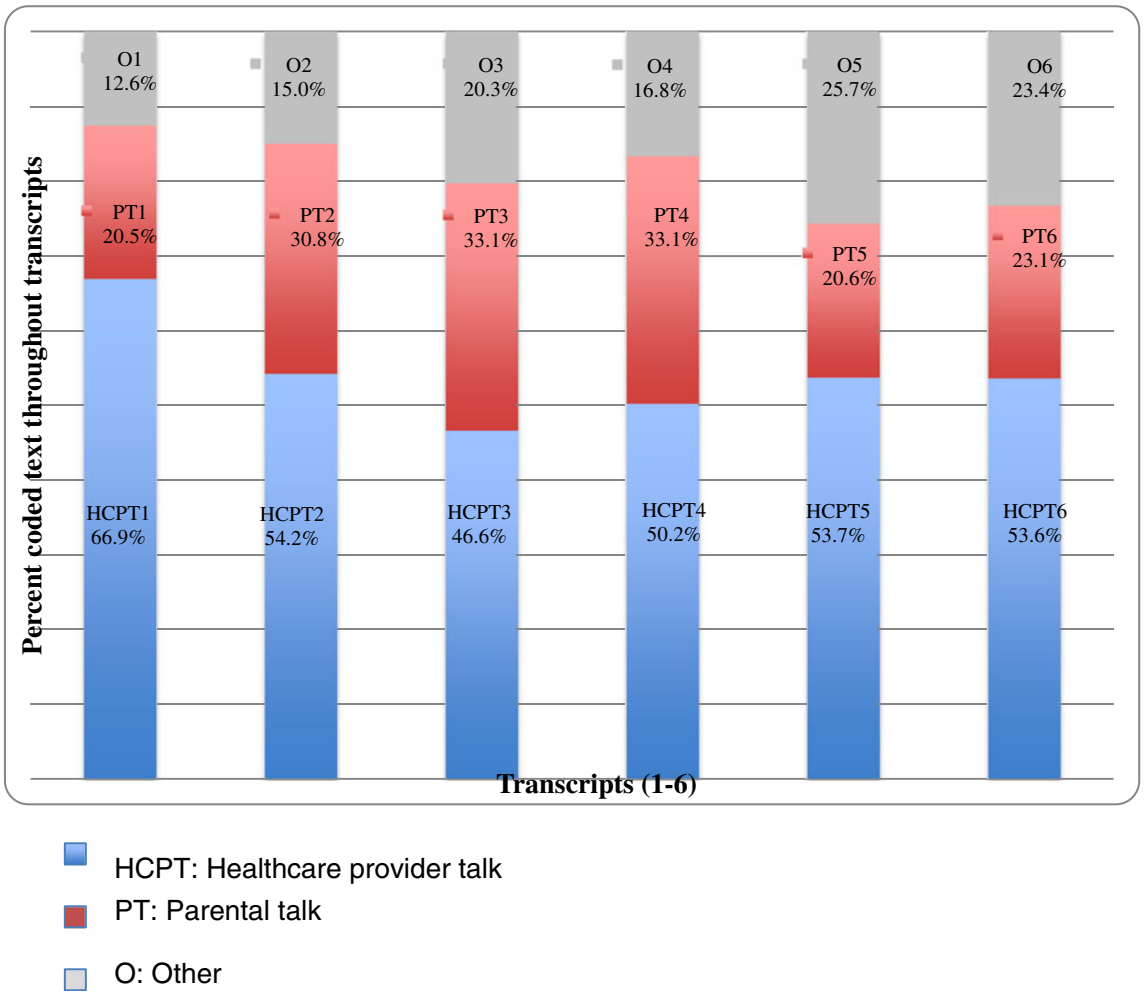

Fig. 1 Verbal dominance per transcript: parents and healthcare providers

Stories were analyzed quantitatively by measuring verbal dominance during storytelling. Although storytelling comprised an average of ~8 % of coded text throughout all the transcripts, parental speaking was close to twice that of the health provider's during storytelling (4.5 % parental vs. 2.2 % healthcare provider verbal dominance). There was a wide range in the amount of parental verbal dominance during storytelling in the transcripts (1.7 %–9.5 %) (Fig. 2). This pattern of verbal dominance during storytelling contrasts with the dynamics of the overall verbal dominance, where the healthcare providers almost double the parental verbal dominance (54.2 % vs. 26.9 %, respectively).

Third Reading Level: Parental Communication

The topics that were discussed during storytelling were diverse and, often, the same topic was addressed in more than one story (Storytelling themes and subthemes are outline in Table 5). In seven stories the main theme was the etiology of the child's diagnosis. Parents made a distinction between their own perception of etiology and the physician's perception. Six stories also discussed multiple aspects of the nuclear family, including struggles with family planning, infertility, genetic testing and relationships between family members. Varied emotions were revealed during storytelling and included fear, shock, surprise, hope, and helplessness. In one of the stories, the parent was "frightened" of the genetics appointment; the parent feared to be told: "It's you!" (¡*Eres tu*!) during the discussion of the familial vs. sporadic nature of the child's genetic diagnosis. In another story, a parent described to feel "scared" (*asustada*) or "frozen" (*helada*) after receiving news of a new pregnancy. In yet another story, a parent felt "at ease" (*tranquila*) or "faithful" (*con fe*) to the prospect of a new pregnancy with a healthy child.

Five stories talked about the natural history of their child's genetic diagnosis, including disease progression and parental reactions and expectations. Lastly, some stories addressed the role of the child as a community member discussing the participation of the child in support groups and the views of community members about the child's genetic diagnosis. As would be expected, most discussions of etiology occurred during the genetics education component of the session (3/5 stories that

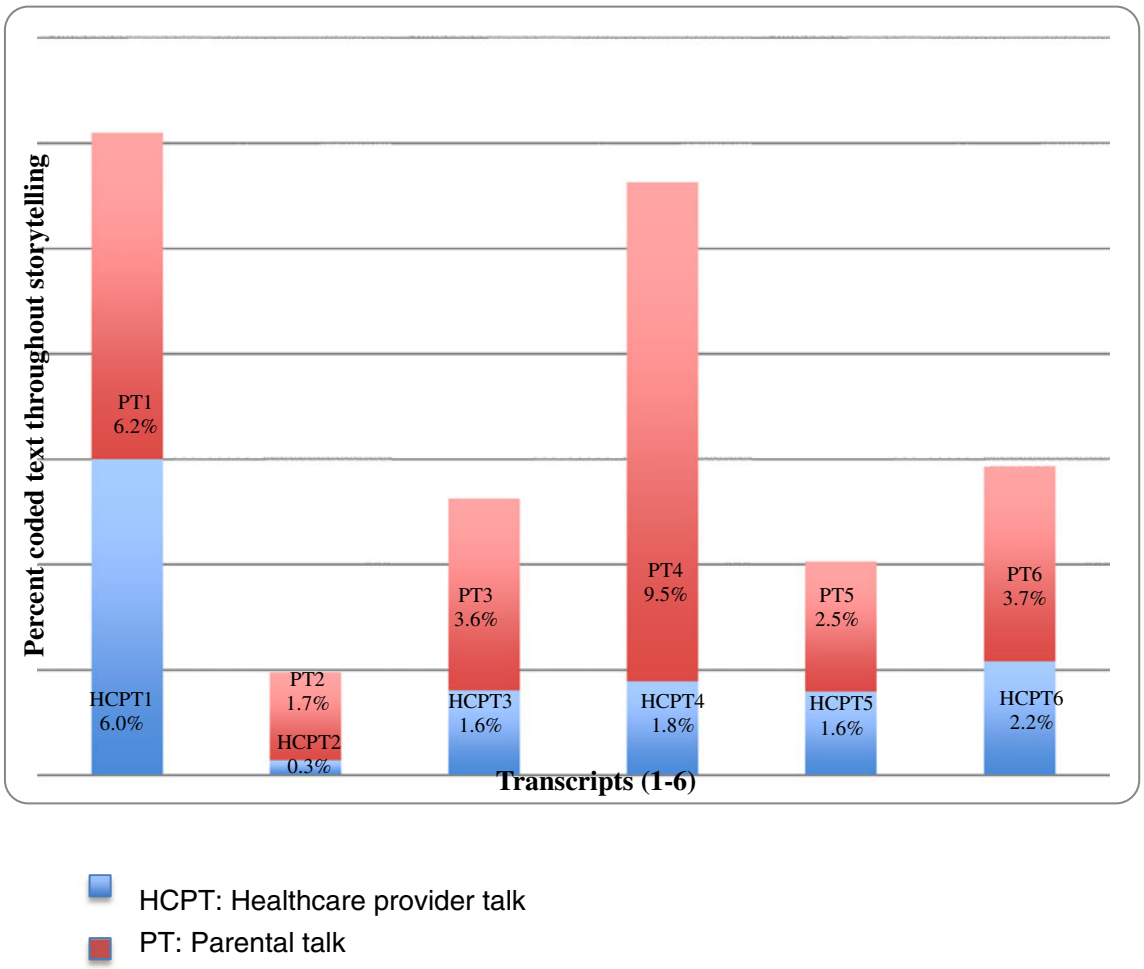

Fig. 2 Overall verbal dominance within storytelling per transcript

discussed etiology) and the stories that developed during medical education and physical examination discussed etiology and the role of the child as a community member (2 stories).

By coding storytelling, we were able to identify contextualization and parental competence as major themes of parental communication (Table 6). Parents seemed to be striving to create a cognitive and emotional context for the child's genetic diagnosis. Parents frequently asked the question: "Why did this happen to me?" and rationalized the diagnosis by engaging in an elimination of risk factors that did not provide them with specific answers (Table 6). In general, the stories showed that parents had a limited understanding of the genetics of their child's condition and contextualized the child's genetic diagnosis by using family history as the setting to understand inherited etiologies (Table 6). They were exploring the implications of the child's genetic diagnosis on other family members, trying to understand their child's developmental milestones and recurrence risks. These stories appear to highlight parental attempts to manage deeper emotional issues surrounding the diagnosis.

Parents also came across as competent caregivers who openly discussed the interaction the child had with family members and the larger community (Table 7). Rather than being isolated by physical or intellectual disabilities, children seemed to be socially integrated and valuable community members participating in support groups and the larger society. Parents also showed their competence by sharing stories that highlighted how they effectively navigated the healthcare system and served as medical advocates for themselves and for the child.

Discussion

We explored parental communication via storytelling in a Chilean, pediatric genetics clinic and found that genetic counseling sessions in Chile and the United States follow a similar structure. We were able to locate seven components of a genetic counseling interaction that are commonly defined in a US-based model of training and clinical practice

Table 5 Storytelling themes and subthemes

Main themes	Subthemes
Etiology	Parent perspective: Unknown, familial, blame-search
	Physician perspective: sporadic, using numerical incidence, not familial
Family	Infertility
	Relationships
	Family planning
	Familial risk
	Genetic testing
Emotion	Fear
	Shock
	Surprise
	Confusion
	Helplessness
	Hope
Natural history of genetic diagnosis	Child's progress
	Parental expectations
	Child's behavior
Genetic diagnosis and the community	Support groups
	Community perceptions of the child's diagnosis

(Hampel et al. 2009; Walker 2009). While these structural similarities are not unexpected and may reflect the fact one of the 2 medical geneticists who provided services in this study was trained in the United States, it is important to note that overall there is a difference in the amount of time that was spent in each session component when compared to previous reports of genetic counseling sessions in the United States. The Genetic Counseling Video Project (GCVP) is the largest study to date in the United States to describe the genetic counseling communication process (Roter et al. 2006).

Using simulated, new visits in prenatal and cancer genetic counseling scenarios, the GCVP used the genetic counselor's speech to assess patterns of communication and counseling practice. They found that information gathering and discussion of psychosocial issues represented 10 % and 9 % of the counselor's dialogue, respectively. Discussion of clinical information comparable to what we defined as genetics education comprised 47 % of the counselor's dialogue in the GCVP (Roter et al. 2006). Although our transcript sample represents return visits, the genetic counseling providers were physicians and our study design is substantially different, the data from the GCVP contrast with our findings, where information gathering, psychosocial counseling and genetics education comprised 34.8 %, 1.5 % and 17.7 % of coded text, respectively. Future studies using coding schemes similar to the Rotter Interaction Analysis System (RIAS), which was used by the GCPV, will be helpful in comparing genetic counseling communication process in international settings.

In the analysis of ten genetic counseling sessions conducted in Canada dealing with a new pediatric, genetic diagnosis, Babul-Hirji found that counselors verbally dominated the interactions and communication was overall asymmetric (Babul-Hirji et al. 2010). However, communication was more symmetric when parents were given the opportunity to share their health experience (Babul-Hirji et al. 2010). Our analysis of verbal dominance also shows that communication was not a balanced two-way process in our sample and providers were the primary communicators throughout the sessions. In spite of this dominance, our study of return visits found that parents were significant contributors to the verbal communication in the sessions (~1/4 verbal communication).

Furthermore, parents were able to direct portions of the clinical interaction with their health care providers and used storytelling as an open communication space. In previous studies of adult, outpatient medical settings, Cordella found that during storytelling, patients described their emotional state and physical symptoms, expressed concern about the treatment or management of their health condition and shared their difficulties complying with medical recommendations (Cordella 2004a, b). Although Cordella's storytelling themes parallel ours, we uncovered new important themes specific to the pediatric genetic counseling setting such as the discussion of etiology and the role of family. Parents are using storytelling to explore aspects they consider important in the parenting of their children. They seem to strive to contextualize the child's genetic diagnosis and convey their competence as caregivers. Although our study did not code for the coping process or coping strategies as traditionally defined in the literature (Lazarus and Folkman 1984), storytelling shows us traces of dynamic cognitive processes and behaviors that parents use to face the child's genetic diagnosis. Thus, although healthcare providers were the primary communicators during genetic counseling sessions, parents seem to be using storytelling as a valuable space to help them understand and gain control over the child's genetic diagnosis.

In a US-based model of genetic counseling, we would expect that parental exploration of contextualization and competence would traditionally be elicited during psychosocial assessment and psychosocial counseling. The fact that these sessions had limited focus by the clinician on psychosocial assessment/counseling did not prevent parents from identifying mechanisms to explore these concepts. We found that storytelling provided a means by which parents could highlight their concerns. In a pediatric setting, storytelling can be a powerful channel to elicit emotional, psychosocial and cognitive aspects of the parental lived experience with a child's genetic diagnosis. Survey-based and focus group studies often report that parents feel anxiety, burden, guilt, isolation, and depression in

Table 6 Parental communication themes: contextualization (HCP: Health care provider/*PDS: Proveedor de salud* PARENT/*PADRE*)

Parental contextualization and subthemes	Transcript excerpt (English)	Transcript excerpt (Spanish)
Contextualization: Etiology (Transcript 4-Panhipopituitarism, CL/P)	"PARENT:I don't t know what it is due to	"PADRE: no se a que se deba
	HCP: what it was due to…	PDS: a que se debió…
	PARENT:I just remember that when the (child).. about everything	PADRE: Solamente me acuerdo que yo que cuando el (niño) XX de todas las cosas
	They told me that it was, it was like a percentage…	Me dijeron que era, era como un porcentaje…
	HCP: I see	PDS : ya
	PARENT: like out of a million, one is born; he was born	PADRE: de un millón nace uno, nació el
	HCP: I see, that it was his turn, I see	PDS : ya, a el le tocó, ya
	PARENT: that, that is what I know, what I understand	PADRE: eso, eso es lo que yo se, lo que tengo entendido
	HCP: ok"	PDS : ya
	PARENT: but why, I have no idea	PADRE: Pero por qué no tengo ni idea
	I don't know po'©	No se pos
	Me, being healthy	Siendo que yo soy sana
	HCP: right	PDS : claro
	PARENT:I mean, I don't drink or anything	PADRE: o sea, yo no bebo ni nada
	I don't smoke, I don't do drugs…nothing	No fumo, no hago drogas… nada
	HCP: right	PDS : ajá
	Of course"	Claro"
Contextualization: Family (Transcript 1-Translocation Down Syndrome)	"PARENT: I see, I think XX I think that [the problem comes from me]	"PADRE: ya, yo creo .. XX yo creo que viene por [mi el problema,]
	HCP: [that, we need to confirm that]	PDS : [eso, eso tenemos que confirmarlo]
	PARENT: because I have two miscarriages as ((a)) precedent	PADRE: porque como antecedente, yo tengo 2 abortos
	HCP: you miscarried [so it could also have been ..]	PDS : tuvo aborto [entonces también pudiera haber sido..]
	PARENT: [my sister] has miscarried	PADRE: [mi hermana] ha tenido aborto
	HCP: uhu	PDS : aja
	PARENT: my brother had problems to … also to.. be fertile, so I think that it comes from that side	PADRE: mi hermano tuvo problemas para.. también para.. fecundar, entonces yo creo que por ahí viene
	HCP: it could be an explanation, it could explain all that"	PDS : puede ser una explicación, puede explicar todo eso"

Table 7 Parental communication themes: competence (HCP: Health care provider/*PDS: Proveedor de salud* PARENT/*PADRE*)

Parental competence and subthemes	Transcript excerpt (English)	Transcript excerpt (Spanish)
Competence: the child's genetic diagnosis and the community (Transcript 6-Down Syndrome)	"PARENT: the people who see her, they tell me.. they don't believe me that she has Down Syndrome	"PARENT: las personas que me la ven, me dicen…no me creen que tiene síndrome de Down
	HCP: yes, every… every child is [different], it's not like all children…	PDS: si, to… todas las guagüitas son [distintas] no es que sean…
	PARENT: [different], yesterday, the lady told me, no, she told me, they have to repeat that test in particular on her, she told me, because no, not that child ©. I tell her, no, but it's not like it is not, the thing is: she has it."	PARENT: [distintas], si la senorita de ayer me dijo, no… me dijo, tienen que repetirle ese examen en particular, me dijo, porque esta guagua no. Yo le digo, no pero no es que no sea no, es que ella lo tiene."
Competence: support groups (Transcript 6-Down Syndrome)	"PARENT: no, because I'm really happy in the support group	"PARENT: no, porque estoy super feliz en el taller
	HCP: I am so happy… I am so happy to hear that	PDS: me alegro tanto.. me alegro mucho escuchar… de eso
	PARENT: yes… no, I'm happy, because, the thing is they had told me, like she …. She was never going to hold up her head, like she was going to struggle, like….	PARENT: si… no, estoy feliz, porque igual a mi me habian dicho, como que .. nunca iba a afirmar la cabeza, como que le iba a costar, como que…
	HCP: ahh, who told you that? < @hahaha@>	PDS: ahh, quien le dijo eso? (laughs)
	PARENT: the thing is.. with the people one hangs out…	PARENT: pero es que con personas que uno se junta, pos
	HCP: yes…	PDS: si…
	PARENT: what do you do then if you listen to everything?.... well, then, yes, like I am happy now.	PARENT: que hace entonces si uno pone oido a todo?.. entonces si como que ya si estoy feliz
	HCP: yes, that's the most important, I mean… people comment or state opinions on things with good intention…"	PDS: si, lo mas improtante es eso, o sea la gente con buena intencion comenta y opina cosas."

response to a child's genetic diagnosis (Ablon 2000; McGowan 1999; Skirton 2006). By further cataloguing the relationship of these themes with provider/parent interactions during storytelling, future studies will enable practitioners to recognize and act upon parental communication patterns that would otherwise go unnoticed during the session. This knowledge could be particularly important in helping to establish and expand cultural competence in environments within and outside the United States, where providers may not be fluent in the cultural norms of their patients. Thus, it may be appropriate to consider ways in which structured spaces for storytelling could be integrated into culturally diverse genetic counseling scenarios.

Our analysis found that there was a substantial focus on genetics and medical education in the follow-up clinical visits we studied. Based on our observations of other medical genetics encounters in this health care system, we believe that it is highly likely that the initial clinical visits had addressed issues of heredity and recurrence risks (Margarit and Ordonez unpublished observations). The fact that the parents in this study had many unresolved questions and concerns about these topics highlights the importance of integrating structured genetics education components into the genetic counseling session at different points in time in the relationship with the patient. Although the Chilean definition of genetic counseling proposed by (Revel 1995) places importance on an educational component to the sessions, our participants are telling us that a one-time "exchange of scientific knowledge, data and facts" may not be sufficient. Over time, evolving needs may prompt individuals to revisit and re-conceptualize genetic information and its impact on decision-making and adaptation. This process highlights the importance of creating space to support the educational and psychotherapeutic aspects of the genetic counseling process (National Society of Genetic Counselors' Definition Task Force, Resta et al. 2006; Kessler 1979; Targum 1981). In contrast to the US-based definition of genetic counseling, which integrates education, interpretation and counseling as three key components of the counseling model, the sample Chilean definition focuses on education. Although Chilean patients may engage with the education, interpretation and counseling components of a session differently from those in the US, our results suggest that cultural differences should not limit the inclusion and re-inclusion of these three components in the longitudinal counseling process.

As an exploratory research study, our study has a number of limitations. Perhaps the most significant is the small sample size of our study. Since our two genetic counseling providers were physicians, it is also difficult to compare our findings to other genetic counseling scenarios where masters-trained genetic counselors are the counseling providers. Additionally, our research was not a formal linguistic study, which limits available methods to investigate communication patterns and other tools aside from storytelling that may convey similar themes about parent communication. We also did not use external coders, transcribers or translators due to funding limitations. Lastly, even within the context of Chile, participants in this study were part of a convenience sample, which is not representative of the entire Chilean population.

Our study analyzed communication dynamics between healthcare providers and a patient community of limited financial and educational resources. The community where *Hospital Padre Alberto Hurtado* is located is one of the metropolitan regions in Chile with the highest psychosocial risk indicators: domestic violence, unemployment, depression, drugs and alcoholism addiction. Furthermore, the educational level in the community La Pintana, one of the communities serviced by the Hospital, shows that for individuals aged 15 and older the average schooling is 8.46 % and illiteracy rate of 8.02 %, which contrasts with Chile's overall illiteracy rate of 1.4 % (Ministry of Social Development, Chile [*CASEN*] 2009). Thus, data about verbal dominance of parents and healthcare providers and parental communication themes may vary in larger samples from different medical and socio-cultural settings within Chile and other Latin American countries.

This research lays a foundation for further work in pediatric communication studies in Chile and other international communities. Future studies should characterize variables that may affect the communication process between parents and healthcare providers, such as parental level of education and the length of time a child has been established as a patient in the genetics practice. These factors may influence verbal dominance, the structure of the genetic counseling session and parental communication themes. Future studies should also conduct qualitative assessments of the genetic counseling provider's discourse in Chilean and other international counseling settings. Counseling providers may be found to use particular prompts and communication patterns to elicit specific storytelling themes or other communication dynamics not described in US-based providers.

In summary, contextualization and parental competence emerged via storytelling as parental communication themes in a Chilean, pediatric genetics setting. Although different sociocultural and legal environments outside the United States will modify some aspects of the genetic counseling process, the structure of the genetic counseling interaction and parental communication themes may be more similar than the differences that exist socially, ethnically and culturally between these two communities.

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