

Supplemental Digital Content 1 – Table of the extra verbatim of the interviews

Listen and be listened to	
Access to new information	Physician G – <i>The mediation made it possible for the mother to finally express herself, since we hadn't been able to communicate with her before. And the father also stated his culturally-related difficulties, which we didn't get before.</i>
Intimacy – Access to another level of communication	Focus Group – <i>We had good communication, and we wondered, why did they not tell us before? It's as if the patient forbade himself to tell us things we couldn't hear.</i>
Understand and be understood	
Understanding of the disease and its possible consequences	Father Family H - <i>My wife didn't understand the risks related to the disease, but with the mediation she understood.</i> Father G - <i>The mediation was OK for me because I could get answers to all the questions I had. I felt reassured. It helped me to understand the disease.</i>
Understanding of the child's behavior	Physician A - <i>It allowed us to understand why the child was so isolated, and why she wasn't talking to us.</i>
Families' need to be heard about their daily problems with the sick child.	Father Family F - <i>For me, if this mediation has allowed some [of the staff] to understand, that's already enormous"</i> Father Family E - <i>During the mediation they understood, it's a child, it's the disease that makes him like that.</i> Focus Group – <i>The families don't need us to agree with them, they need us to listen to them. The doctor needs for the patient to adhere, but the patient just needs the doctor to listen and recognize his or her distress. If the patient says, "that hurts me, that makes me sick," and if the physician can listen to that and can understand that what he is doing is hurting the patient, because it is to cure him, then the patient finishes by adhering.</i>
Physicians' need for their intention to cure the disease to be understood	Focus Group - <i>The alliance is important for physicians. They need the patient to believe that they are sincere in what they are doing, when they commit themselves to do everything they can to care for the child, especially if things go badly.</i> Focus Group - <i>The physicians are not monsters, but what the drugs they give the patient do is monstrous. It's not easy for physicians to free themselves from the idea that they are monsters.</i>
Access to a dimension of universality that makes it possible to overcome the obstacles	Focus group – <i>Mediation is a group moment, which creates a communion, which touches the universal human dimension. It's a sharing of an intimate part of our universe; afterwards, it is possible to step aside and to listen to something from the other.</i>

Trust and be trusted	
<p>The physician is reassured that the mother understands.</p> <p>The mother explains that even though it is painful for her, she follows the regimen that her son must have.</p>	<p>Physician G - <i>It was important for us, because we saw that she understood well. Even if she was not always doing what we wanted, she was following the diet, she was sensible.</i></p> <p>Mother G - <i>It is very difficult because I would like my son to eat everything like other kids. But he can't. He asks for it, he wants to steal my food, I always say no, and he cries. This makes me very sad.</i></p>
Combine everyone's resources	
<p>The family and the medical team participate simultaneously in the child's plan</p>	<p>Physician G - <i>The physician-mediator stressed strongly that it was necessary to do both at the same time. That she do everything so that her grandchild could be protected like any other family member would be, do all the rituals, baptism, everything that was necessary for that, and that at the same time, that we continue to take care of him and see, if the levels really did not move, that he wasn't sick and that everything was well, that we redo the genetic testing. The grandmother agreed. The mother also.</i></p>
The limits of mediation	
<p>Difficulty for the physicians of letting go of the idea that they had to convince the family</p>	<p>Physician D – <i>Since there was no consensus, finally, maybe a consensus was too much to ask for, but nonetheless something common that could be shared, on the idea that the child is disabled, that he has a disease and that it's necessary to support him with this disease, that it's complicated to work together.</i></p>