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| Appendix B. Example Caregivers Quotes for Emerging Themes | |
| ***Orientation to PAP*** | “It took me probably a good six months to a year to figure out who did what … it was a lot of information. It's almost as if I needed one person, kind of like a coordinator, to say, ‘Oh, okay. If you're having this problem, we need to go to that person and that person,’ instead of trying to figure out who I needed to call or to ask questions … If they had that coordinator person in the room that said, ‘Okay. Now, So-and-so's going to come in and you're going to talk about this. And, this is the reason.’ Instead of the person that showed me the CPAP and how to turn it on; he would leave, and then all of a sudden somebody else would come in. It's just like, ‘Okay, who are you?’ You know? [Someone to] kind of walk you through that.”  “They gave us a handout and when [the provider] came with the machine and one with all pulmonologists. They've just talked about what the CPAP machine does and how it helps the sleep apnea, why she should wear it, and how it would be beneficial.”  “They gave us literature about it and I guess I didn't have a lot of questions just because we have a good friend that also has Down’s syndrome that’s a few years younger than her that has been on CPAP, like, around the same time that [Child] was diagnosed a little bit before. I had talked to her mom and she’s given me information about how she did, her daughter did.” |
| ***Strategies for Introducing PAP*** | “So initially she was pretty young, around two. And so, we couldn’t really speak to her about it in a way that she could understand so we had some support from the nurse. Then subsequently she became a preschooler and we started using some flip charts and picture format so that she understood the process steps at bedtime.” |
| *Patience* | “Just slow down, introduce it, let the child help dictate the timeline. That was a big mistake that we made. We didn’t, we dictated the timeline to her, when she should have been more involved and included in that process. This is something that's going to be with them forever, so taking those couple of extra days to figure it out. Things to help make it their own and give them some ownership of it. Like I said [Child] was thrilled when we bought ribbon, she got to pick out different ribbons. To be able to tie around the tubing. So it's like we might be defacing the machine, but it feels a little bit more like hers then.” |
| *Visual Aids* | “I have been kind of thinking of maybe a little book to write about children with sleep apnea and Down Syndrome or a little skit or something 'cause if there is one out there, it's hard to find. I felt as though that they need information on their level that they can understand because I am still trying to get my daughter to understand … Like I guess as far as what happens to them when they are sleeping. And preventative measures that they can take for those things not to happen. I guess somebody that looks like them and that is going through the same thing as them. Someone that they can identify with, I guess.” |
| *Mutual*  *understanding*  *between*  *caregiver and*  *child* | ““[It was] very challenging … It’s even more challenging for a child or infant. Now she’s a teenager and she’s able to make better choices about wearing the CPAP. She still feels uncomfortable wearing when she’s congested. And then sometimes she will still refuse to wear it because it’s just not a comfortable piece of apparatus. But we do the best we can. If we can get 50% usage in a week, we consider that to be a success.”  “The CPAP has two types of tubes. One is the connecting tube to the mask, and then the other one is the kind of longer tube that attaches to the machine itself. I had her wear it even with the shorter tube, and she kind of looks like a little elephant with it! So, I kept saying you have a trunk, you know. And then I’ll put it on – as best as I can because it’s a smaller mask. And then I’ll show her that I’m wearing it, so it’s fine.”  “Another thing that [the care team] did not really recommended, but actually came from my husband, is he just started talking to her a lot about our heart and how wearing it, it doesn't feel like you need it to sleep, but it helps her heartbeat right, and it's going to keep your heart healthy and that seems to help. When you ask her, why do you wear a CPAP, she says, ‘It's to protect my heart, make my heart work right,’ so that has been helpful. It was really just a trial and error of trying to figure out what she would think was important enough to keep that thing on her face.” |
| ***Nighttime adherence*** | “I was really like, ‘How was she going to sleep with air blowing in her face and a mask on her head when not sleeping?’ I think I was more nervous than she was because after the first week of it we had no problems. I used to just sit there, wait for her to fall asleep to make sure everything is okay when she first fell asleep. But after the first week and a half, she’d take it off; she’d know how to unplug it to go to the bathroom. She is perfect with it now.”  “There was a psychologist who talked to us about strategies and rewards. But the difficulty was not in getting my son to wear the mask, it was the difficulty is always getting it to stay on all night.”  “When we did the sleep study they [recommended we] go step by step with it. They don’t just push him on it. They go step by step so they can get used to it. But that’s about it, but he still has his days.” |
| ***Barriers to PAP Adherence*** | |
| *Mask and airflow sensitivity* | “The air comes up and it hits him in the eyes which freaks him out. If he hears it, like the pinholes are on the side and he hears it, the air coming out, the exhaust coming out, he flips out over that. If it comes unsealed and he hears it he'll flip out and take it off.” |
| *Finding the right mask* | “They tried just the nasal mask and that wasn't the solution. We ended up having a full mask. So, she has one that goes all over her nose and her mouth. She has sensitive skin issues, so that was another problem as well, her mask was causing her to break out really bad. It may just have been specific to us and just our own experience. I don't know how that would be relative to anyone else. Personally, I just felt like there was a little bit of a disconnect between [Home Health Agency] and her care team.” |
| *Logistics and supplies* | “Because once that filter needs to be changed, she’ll be coughing, and you know the air that's coming in is dusty. That's when I know if I don't have any filters she can't sleep. They’re pretty good with shipping them off once I call the next day, it’s in the mail the next day itself. She might need to sleep with the machine one night if I don't remember. I put it in my phone, so the insurance only pays for it so often. I make sure as soon as it’s available I order it but you got to stay on top of those filters because with [Child] it seems like it bothered her when the filter need to be changed, she would cough and stuff.” |
| ***Child Characteristics*** | “She just seemed to take it pretty well. She generally sleeps on her back and we helped her get the mask on. Now, over the years we've taught her how to take it off in the morning, how to turn off the machine, how to open the water chamber and she does all that herself now. She gets up, she takes off, she turns the machine off, she opens the chamber so the air is out. She's become pretty independent. I think if you were to track her usage, she probably wears it nine hours every night.”  “They made suggestions, but again, it was really pretty easy with her. If she took it off in the beginning, I just woke her up and put it back on. In our family, it really wasn't a big deal for her. She's been very compliant.”  “No, she is afraid of her -- I think she doesn't like her room. More than anything, I think she is -- I think she's using it the opposite way, like holding the machine against us, like I’ll keep it on if I stay in your bed.”  “With [Child 1], then she just thinks that she's being punished, and she can't get out of bed, and this is like a strap that's holding her into the bed. Does she think or does she understand that she could take it off and come up and get us or go to the bathroom? We tried to say that to her, but I don't think she understands that because she will not even ask for basically anything. |
| ***Suggestions and Advice for Families*** | |
| *Positive*  *Reinforcement* | “I would definitely say make the mask. Again, make it fun. Make it something that they're not scared of … We got the mask a couple weeks before we ever got the sleep study. We let him play with it, we let him put it on, we let him be an elephant. Let him just play with it on a day-to-day thing while you're waiting for your BiPAP or CPAP to come in. Let them really just make it part of their day.” |
| *Social Support* | “I know with HIPAA it probably could never do this. But I think it would be nice to have another parent who was in the same spot. I don't know, having a child with special needs can sometimes be lonely. Usually, you feel like you're the only one that's having to do certain things.” |