

Box 7: Burden on Familial Unit

[7a] Parent participant (10010): *"I'm like, oh my God, she never would've been able to do this...It would've impacted our lives, as well...just your daily life and meal planning. Those little things that I sit and think about, when I get overwhelmed with anything going on in her life now, I'm like, what would it have been without [transplant]?" and then I'm like, okay, I'll take it."*

[7b] Parent participant (10011): *"Before it was every night I never left things undone because it was always, oh, is tonight a night we're going to have to race off to the hospital?...Like I said, [transplant] changed our lives in a lot of ways."*

[7c] Parent participant (10017): *"It really impedes your life, your family, and I wouldn't want that for any new family. If we could protect them and they don't ever have to go through it, and if transplant is safe, with it being as safe as it is, then that's always an option. That's the best option...the lack of sleep and constant worry, completely sleep deprived because you check to make sure they're fine all night long. The stress of what if something happens, that takes many years off your life."*

[7e] Parent participant (10013): *"That has definitely been a challenge, just to have a healthy amount of and realistic amount of worry, not to let yourself fall into that pattern of panicking...this condition is not for the faint of heart. Managing it, I'm not going to say it's easy by any means, but it is doable...Despite all of our ups and downs and things we have to go through when we think she's sick, I'd still rather deal with that than have to deal with X% dying and all the issues that come with having a major organ transplant... I just don't see a reason. The path unknown is really frightening to me, and there's no reason for us to go down that path unless we need to."*

[7f] Parent participant (10027): *"Right now, he is living a 100% functional, wonderful life. Getting a liver transplant would just be replacing his urea cycle disorder with another condition. He would be on...immunosuppressant drugs for his whole life. I feel the way I manage his urea cycle disorder, I would have time if something were to happen. If he were to get the flu, or some horrendous illness that would spiral his urea cycle disorder into a horrible ammonia attack, we'd have time to deal with that....If he gets the flu, I can usually manage it from home...I feel like if it was a liver rejection, and say there wasn't another liver available, I wouldn't have all these options. I wouldn't have the options to save him the way I could now with a urea cycle disorder. That's why I've chosen not to transplant him."*