

Medical Home Phone Conference
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Care of the Caregiver
Lisa Samson-Fang, MD and Nancy Murphy, MD

Nancy Murphy: For the past few years I have been focusing on caregivers. The reason for my focus on this rather than focusing on the child is that I realized as practitioners we prescribe medications, recommend therapies, regimens of play, behavioral interventions and the demands can be very complex when taken in the context of a parent who may be trying to juggle a marriage a household and other siblings. I began looking into the literature and where I want to start with today is the concept of informal caregiving. Informal caregiving is different than what we think of as formal caregiving where nurses and doctors and therapists and teachers are rendering services and informal caregivers is somebody who is the primary caregiver, typically a parent or it may be a guardian or a grandparent. But it essentially becomes the parent who is put into this informal caregiving career. Think about typical careers; we select them, we train for them and we can get promoted in them or exit out of them. The challenge of an informal caregiving career is that it's not chosen, you don't get a paycheck for it and it's been described as politically and socially invisible work. So there is not that recognition of the amount of responsibility that one takes when they become an informal caregiver. In that concept, let's look at what happens to caregivers. When we look at the literature, and most of this is based on parents of children with cerebral palsy, we're seeing that parents who have a lot of physical care responsibility for their children frequently complain that there is chronic physical conditions such as back pain, migraines, headaches stomach ulcers are more common in parents of children with cerebral palsy relative to other families. Another study has shown that caregivers of technology dependent children have more guilt, more anger, more frustration, more depression and more sleep deprivation. The study we did in Utah in conjunction with DSPD about two years ago and we gathered up through the Utah Family Council, 40 informal caregivers. Those were parents or guardians of kids with any kind of physical or developmental disability. Our study group ended up having 10% of participants divorced. The mean age for participants was 45 years and the mean year of the children they were taking care of was 13. We held 4 focus groups talking about the experience of being an informal caregiver, what needs did they feel were not being met and what we could do to support them in this role. Through the course of this dialog we came out hearing that there were five themes to care giving.

The first theme was that care giving is stressful and that they attributed this stress to lack of control. For example one parent said, "I'm always waiting for the other shoe to drop. This sense that things are okay right now but if my child has a seizure, everything I've planned is going to change." Or "if I send my child to school I wasn't expecting the school to call me and tell me to come pick him up he's not doing well." So this sense of unpredictable or uncontrollable parenting was perceived as a major source of stress. They also told us that they had too little time to do too many things. There is a constant pull between what "I'm doing for my child with a disability as opposed to what I may be doing to my typically developing child or my spouse or my career or my house and at the very bottom of the list is what am I doing for me." Parents also said that the need to advocate became burdensome at times. They felt like they had to make

a lot of noise, be the squeaky wheel, state their demands with great exertion because that is what it took to get their child's needs met and that left them angry and frustrated. That was theme number one Stress.

The second theme we heard is that their care-giving role absolutely had a negative effect on their own health. When we asked how their health compared one year prior to that conversation, more than half of them told us it was worse. Only six had gotten better. The majority of folks were holding on complaining primarily that sleep deprivation and fatigue were the major limitations. Among the physical complaints was back pain, shoulder pain. There were a few participants who felt like their physical health was compromised when their child got combative. They may take a slap to the face or get tangled up in trying to keep their child safe when actually the caregiver is the one who sustains injury. Also in the category of impact on health, they described the negative impact on their emotional wellbeing. It's stressful and the sense of burnout, which they related to having no end in sight. When we think about care giving for an adult caring for aging parents it seems a more acceptable phenomena that may have an end point that is a natural progression. However, when we think about raising a child with a disability and typically we determine teenage is the age when a child should be functionally independent and now needs guidance in terms of emotional social needs, but for a child with a disability their dependency may be lifelong so the idea that this career will never end was a major source of emotional stress.

The third theme we heard is that caregivers have a concept of sharing the burden and if they could find someone to share it with, be it a spouse, a grandparent, respite care whatever it may be they found it to be a very uplifting source for them. We hear that families lacked respite. And even when respite was there it wasn't always reliable and perhaps not always with the degree of competency that would give caregivers the comfort in knowing that their child is in good hands. We heard about other caregivers who were still on waiting lists for respite. So it's hopeful but not readily available and not always competent. And in terms of sharing, sharing can be calling another parent who has a special needs child, getting out of the house and participating in the community and school so you don't feel like you are alone.

The fourth theme we heard was worrying about the future. A feeling like when I'm not here to take care of my child who will be. Tied into feelings of uncertainty.

The last theme that we encountered was care giving coping strategies The coping strategies were clever and practical. They would take a mini break and go to the bathroom for ten minutes to be by themselves, cry, go shopping, eat chocolate, call a friend. Families said it's not all bad. We heard from caregivers that there is a positive aspect of work. One family said it made them feel good that they could care for a child with disabilities. Families said it made them more compassionate. Siblings developed a sense of responsibility, the ability to wait, to be more patient, some siblings were interested enough to go into health care careers themselves.

These five themes we heard from the families here in this state were consistent with what we read in the literature which is, if caregivers had a bit more support so that they could take care of their own needs as well as the rest of their family, that sense of burn out would be less and their health and wellbeing would be greater

We know from the literature that when caregivers are in trouble, 30% of hospitalizations can be related to the lack of community and respite services and another 30% is related to medical and physiological issues among family members. Day to day stress is the major factor that we add to “at home” placement, which were not what families had anticipated. Overall we heard that families need more support, more respite and that's its okay to take care of one's self.

In a sequel to that study on parents of children with cerebral palsy, focused on the concept of caregiver effectiveness. This definition: caregiver effectiveness described as providing, technical, physical and emotional care that results in optimal patient condition while maintaining their own health and well being. Well functioning care givers take care of care recipients as well as self.

Lisa Samson-Fang: Any questions?

Question: I wondered if in the research or in the focus groups the parents identified anything that the primary care practitioners already did to assist them with coping strategies or supported them to be effective care givers?

Nancy Murphy: In both studies, in the literature and what I hear from families and what we heard in the focus groups, all the components of the medical home the one that is most highly valued is the family centeredness of care. A Canadian research group has done a lot of studies showing that family centeredness of care does reduce caregiver stress. There is also a concept that if I'm a caregiver who is satisfied with the care that is rendered to my child I feel better about that care. The other part, I didn't mention is that one of the frustrations parents feel is the burden of being a care manager or care coordinator. That is one of the invaluable services that a medical home could provide.

Lisa Samson-Fang: Any thoughts or questions?

Question: Have any of these families found practices that will effectively facilitate their getting what they need?

Nancy Murphy: Like most of us, I am in clinic right now and I had a family who came to me with a very complex kid with multiple diagnosis and a laundry list of medications and this mom came in with a 2 page type written here's my medical diet list of diagnosis for her child. It was exquisite. She is sharing that with her primary care doc, and a lot of this happens with families. There are medical home tools that guide parents in practices and implementing them in making these summaries which may be a bit of invested work up front, but once it's in place and needs minor changes from time to time, it decreases the caregivers stress of having to explain it every time she sees a different doctor. From a provider's perspective it helps us get organized and focused and from a caregiver's perspective – here's what you need and I don't need to repeat myself. It works globally and probably the Medical home site is the best way to guide through that.

Question: In terms of practices facilitating contact between parents do you have any advice or thoughts?

Nancy Murphy: I think in our practical lives we tend to expect the parents to be care coordinators- Maybe its not that the expectation is unrealistic but what we need to do is give parents tools to do it and that's where we fall short. I don't think asking a parent to relay information and to keep the bigger picture in mind is an inappropriate thing. I think it is a huge challenge to them in light of their day-to-day activities to expect them to do that without guidance. Whether it's a practice that goes ahead and initiates that or a family as long as it gets done.

Question: With us in Vernal being in a remote rural area, I found that sometimes some of our caregivers need to talk about their child and that its' okay to cry. We see that frequently, we don't take the place of caregiver's primary doctor but we can also direct them to help them get what they need to make sure their mental, emotional and physical health is being taken care of.

Nancy Murphy: That's a good point. One of the things I hopefully am doing now, but I had to teach myself to do is when we bring a kid to the clinic. We think about what are the problems, what are we going to work on, where are we having trouble. I acknowledge that the parent is doing a really good job taking care of the child. Sometime we forget to look at what is working well and when parents go home from the office and feel like "wow, maybe they get it and they do hear me", I think it's really valuable. Be it tears or a little pat on the back, that emotional connection to appreciating what's been going on is really valued by families.

Lisa Samson-Fang: Other comments or questions?

Comment: I had a comment about the parents doing care-coordination and focusing on the big picture. I think that even in the aspect of the big picture sometimes parents need our guidance. For instance, they might focus on one thing like how their irritation at the g-tube site and it turns into a huge horrible fearful thing for the parents and sometimes it's our role to say "but look how well she's growing, look how well she's developing," and help them focus on the big picture. On the other hand, I've had parents come in and they are very well focused on the big picture but I think it depends on parents. Sometimes they don't just need our help with care coordination but they need our help to see globally how far their child has come and what strides they've made and to focus on the positive and that may take away their future anxiety or their burden with respect to guilt they may feel.

Nancy Murphy: There is a load of responsibility parents may feel when they visit the doctor's office and almost a sense that when they bring their child in, that they themselves are being evaluated. That their child is doing only as well as the care the parent is providing for them. That is stressful. Your point directs us to the family centeredness of care – find out where that caregiver is and then go from there. Until we stop and listen to where the parent is, we are not going to be able to assist them in their particular needs.

Question: I think every parent who comes to clinic leaves with a to do list, which I can imagine is an additional stress, and sometimes it's a to do list that any of us would have difficulty accomplishing in a day's time. How can we help them after they leave the clinic?

Nancy Murphy: If we wait until the tail end of the list it may not be fair. Find out where they are and if the laundry list is huge, first off acknowledge it and then in that encounter with the family give some practical tips. For example one can suggest g-tube care when they do a diaper change or range of motion at the hips at bath time. Integrate all these task in normal life will make sure there is greater compliance with it than it is when they try to do all the things by the book that we tend to do. In the long list of things to be done, I try to pull out for families the priorities of what has to be done. Even if a discussion of what to do if they miss something, so up front there is already a discussion on the reality of care giving – that they will not always do everything perfectly.

Question: I wonder if we should put any emphasis on educating extended family such as grandparents, aunts and uncles? I wonder how much time we are spending with the fathers or grandparents. I have mothers who will say, “My mother is afraid to take care of this child.” I wonder if we can be doing anything to reach out to these family members.

Nancy Murphy: I think you’re right. In our caregiver group we didn’t have many dads. The perspective from the father is a different kind of stress. They need to take care of their wife, but there is a financial responsibility that pulls them. It may be that we are putting so much on one person’s shoulders that we are not sharing the burden across generations. When we get into real technology dependency we often require that two caregivers be trained. Sometimes its not someone under the same roof, it may be a friend, a neighbor or someone from their Church or someone from the school you can count on in a pinch. Perhaps we need to get into this notion of informal respite providers. When we think about the work we as health care providers do, we typically do it in shifts, we get weekends off, and we take a vacation. Caregivers in the home do not get that. We do need to broaden our view of support and encourage people to look beyond. Often we hear care givers say, “ Everyone’s at work, I don’t want to ask for help,” or the sense that no body can take care of their child like they can. However, even though there is nothing like the parent/child relationship, it’s okay to take a break and sometimes just hearing that is enough to get the ball rolling

Lisa Samson-Fang: One question I wanted to ask, as primary care providers, what are the resources that we don’t think about using that might address these problems?

Nancy Murphy: I often refer people to DSPD, which is the Division of Services for People with Disabilities. Also, the school systems are a major source of support and that can be early intervention providers or pre-school programs or the K-12 programs as well. Other resources are most often parent to parent support- through individual support groups, diagnostic specific or otherwise families can get a lot of support and then of course through their local Church group or neighborhoods.

Next phone conference is July 25th.

In Attendance:

Lisa Samson-Fang, Nancy Murphy, Barbara Ward, Gina Pola-Money, Carrie Carter, Budge Clinic, Bear Care, Clinic 6 of UofU, South Main, Bob Terashima, UVP Cherry Tree, UVP Plaza Office, Montezuma Creek, Canyon Lands, Redwood, IHC Pediatric McKay Dee.