

Parents as Information Intermediaries between Primary and Specialty Care: Building Partnerships

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Communication for children with special health care needs (CSHCN)

- **Over half of CSHCN require specialty care annually**
- **AAP, 1999 and 2005: poor PCP-specialist communication is a major barrier to coordination**
- **IOM “Chasm” report: poor communication**
 - fragmentation of care
 - duplication/omission of services
 - unmet needs
 - potential for medical error
- **Potential role of family as partners in care unexplored in this area**

A daunting task for parents?

- **Coping with new diagnosis difficult (but necessary)**
- **Understanding medical information difficult (but necessary)**
- **Serving as sole intermediary between physicians very difficult (and perhaps unnecessary)**



Parents are *de facto* intermediaries

- Referrals: Forrest (PROS), 2000
 - 51% of referrals result in letter at 2 months from specialist to primary care physician
- New England survey, 2001:
 - “frequent” (>60%) receipt of communication by only 71% of PCPs, 28% of specialists
- RWJ study, 2003-5
 - 50% of specialists get no information from PCP prior to visit
 - 31% of SPs had “insufficient information to provide optimal care” at first visit

What is known

- Families want more information about diagnosis and treatment (frequently more than health care providers think) and how *they* can help their child
- Families want links to community resources/support

What is not known

- **The degree to which parents feel comfortable carrying, transmitting, using complex information about their child's illness**
- **How the health care system can support them to the degree desired**
- **What tools/resources are useful for this**

Overarching hypothesis

Parents who are fully engaged in information sharing and joint care planning when their child is referred to specialty care will be able to help facilitate communication between PCPs and specialists and will experience increased self-efficacy in interacting with their child's physicians. This will lead to more efficient medical care, reduced unnecessary medical services, and fewer missed work and school days.

Specific Aims

- 1. To identify and prioritize strategies to increase the capability of parents of children and youth with special health care needs (CYSHCN) to convey and use medical information with their child's providers when their children require subspecialty referral.**
- 2. To determine whether strategies for parents of children served by Medicaid might be different from those for other parents.**

Methods: CWM grant

- **Parent focus groups**
 - **Two primary care practices**
 1. Diverse, university-based, 20% Medicaid
 2. “Suburban Worcester”
 - **Two specialty practices**
 - University-based child neurology practice
 - Community pediatric cardiology practice
- **Five groups of 4-6 parents each**
 - Plan: one group Medicaid parents; others chosen to maximize diversity
 - Reality: only able to recruit 19 parents total; though 10 had Medicaid insurance, separate group not feasible
 - Primary problem: scheduling conflicts!

Focus group script

Discussion questions:

- Specialty visits and **information transfer** between doctors
- Working together (or not) with physicians to **use information to help plan care and make decisions** for their child
 - (for each: good experiences; bad experiences; ideas for improvement)
- Brainstorming about **how parents might be supported** in the role of information intermediary
- Evaluation of prototype “**referral care plan**”, with audiotape of “sample visits” between a parent and referring PCP, and a parent and a consulting specialist

Analysis

- **Content analysis leading to development of recommendations for pilot intervention**
- **Goals of intervention:**
 - **Boost parent self-efficacy**
 - **Improve parent ability and comfort with information transfer and plan-making**

Results so far

When a consultation results in a new diagnosis:

You do comprehend it, but then when you leave it's like there's no time to panic, or think about it later, until you have a moment to yourself. And then you try to think, "What did I hear?", and it's very hard.

[...]There were all these specialists coming in, and one specialist would tell me one thing, the other would contradict it, and thank god for Doctor X [primary care provider], because she's very good at – well, "I'm leaning toward this doctor, or more toward this doctor, and I will help you more understand where we are going from here." Because where do you go, when you've got two specialists telling you two opposite things.

...I would like to see – I don't know if other specialists do it – but if they hand you information, leave, and then come back. Let you sit there for a few minutes and let that sink in, and then come back and ask how you feel. And not, "Here's your stuff, go home and look for your next appointment".

Results so far

When multiple physicians are involved and a complication occurs:

We never knew what was going on with that. We never knew exactly what happened ... the chief anesthesiologist for pediatrics, I don't know if there's a different one, he came and spoke to us a couple of times, but nothing was ever really clear. We never knew where all the air came from. We never knew, you know – they didn't know if it was his esophagus, they didn't know ... **If the whoever, the anesthesiologist, came out and maybe explained more exactly about what he did exactly [sic],...** I kind of heard like from the head doctor [but] we never saw that anesthesiologist. We left him in the OR waiting room and we never saw him again. So that makes me think, "OK, well what happened?," you know what I mean. ...**In a way I don't think that they knew either. ...I don't feel like they were keeping – but I feel like they were keeping from me that they didn't know exactly what was going on.** They tried, you know, to stay cool and calm about everything, but I could tell that they didn't know exactly what was going on.

Results so far

When a consultation results in a change of plans:

I would like to walk away from my specialist with a care plan. You know, something on paper, because I can't remember what they just said ... but I'm not hearing anything – just to have something on paper that I can read, you know, when I'm ready to read it. And even if we have to do the research, in the library or on the internet or whatever, that's OK. But we need a starting point, and we need the correct diagnoses, because sometimes they say these big words and I don't know what they're saying, and I'm trying to spell it out, and I'm not getting it right. So I would like to get something in writing.

Results so far

When reporting the results of a consultant visit:

It's very important – like our cardiologist writes out – every visit – he sent it to all her Boston doctors, her pediatrician, and us. And you know, every specialist who sees a child should write up a summary of what the findings were, if there were no findings, if they need follow-up – that should be detailed in a letter sent to the family and all the doctors involved in the child's care, just so everybody can have it in their file, and if they need to they don't have to chasing it around trying to figure out when he saw who, when and bringing it around – you know, it should be cc'ed. **If you got 6 doctors, send it to all six and to us, so everybody can keep it all together.** So, I mean, it's paperwork but it's ... very helpful ...

Results so far

When making a treatment plan:

When he [ENT surgeon] told me that that needs to be done, that the top of the adenoids need to be taken out... he suggested that we have it in , say, three weeks from whenever we were talking about it. Let's say November. And so I decided to do what he said and have the surgery. Well, if I had known that the surgery was going to be so horrific, that [my son] – he was so sick, and it was Christmas. And he wouldn't even celebrate Christmas, and he had to go into the emergency room because he was dehydrated. **I think if the specialist had given me more information and told me what a long recovery this was going to be, we never would have done it then. I would have said, no – after Christmas.** It was a horrible, horrible Christmas for him. I think that lack of communication there – he just didn't explain things to me.

Results so far:

Tension about the ideal parent role:

I think it's a personal situation. I think each situation is so different, and I think some people can go in there and want all the options, and it can be so difficult when you leave. But I think **given that option** of even conversation, "There are other things down the road. Would you like to know now, or would you like to wait?" [...] And I have found that **more with the doctors that work in a team- the doctor and the nurse**. The doctor comes in, we talk about everything. The nurse comes in and says, "Are you OK? Is there something you didn't understand that I can go back and get the specialist, so they can come back in before you leave?"

Results so far

When making decisions about treatment:

I've had another experience, though. [my son] needed to be on – well, [he] was going to be on a certain medication and, you know this was with the primary care physician, and he said, **“How do you feel about this?”** And I said, “I'm OK with it.” And he said, **“Well, let's call the cardiologist and see how she feels. Are you alright with that?”** And I said, “Of course ...”

Results so far

Using a written care plan: This, first of all, gets you thinking about being proactive about your relationship with your doctor and child and everything else, whereas a lot of people think they're just going to see the specialist and all they're saying is what you have to do. So this is all of a sudden you are participating – this is bringing your attention to participating – and then this is a form that you can fill out. Doctors may choose not to or can't, because of time restraints, we can. And we have a form we can make copies of and we can actually do it. And then you check with the doctor, "Is this what you said?" So we can't put all the responsibility on the doctors. **This here brings it on to us, saying OK – participate in your child's health. It says, "You have a say. You really have something to do here. So take the initiative, and this is some forms." And that's what coaching – what you spoke about before – comes in.** Here, this is some forms. You don't have to do this obviously, but these might be helpful for you. You've got the information handed to you, and it's your choice.

Preliminary conclusions

- **Parents have tremendous insight about communication between health care team members, its role in shared decision-making and its impact on care**
- **Many accepted principles of chronic illness management in adults (team care, shared decision-making) are perceived by parents as vital in communication**
- **A written care plan is perceived as very valuable by parents, and the draft form is likely to be useful as a prototype with few changes**

Next steps

- **Revise care plan draft based on feedback**
- **Finish qualitative work, when more funding available**
 - Latino parents, Medicaid parents
 - Physician focus groups to refine care plan and develop protocol for referrals
 - Test referrals in sample of pediatric and subspecialty practices
 - Feasibility
 - Effect size for clinical outcomes: duplicate/omitted tests and treatments, lost work/school, ER visits
 - Funding applied for from HRSA/MCHB and RWJ, using these findings as preliminary data



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