The Quest for Knowledge: The Search for and Meaning of Diagnosis for Parents and Providers

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Child Mental Health Care Context

- High level of unmet need for children with a mental illness (U.S. DHHS, 1999)
- Fragmentation of children's mental health care (Stroul & Friedman, 1986; Burns, et.al., 1996, Farmer, et.al., 2003)
- Identified barriers to seeking services (Owens, et.al. 2002)
    - Perceptions (Recognition of the problem)
    - Structural (Financial, Resource Availability, Policy/regulatory)
    - Experience (Personal dissatisfaction with services)

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Parental Help-seeking Behavior: Identifying Pathways to Care

- Recognition of Parents' key role in the initiation and continuity of treatment for children (Srebnick, et.al, 1996; Costello, et.al, 1998; U.S. DHHS, 1999)
- Need to better understand how parents seek mental health services for their children and what helps or hinders them on the various pathways they take to obtain care (Costello, et.al, 1998; McLennan, et.al, 2003)

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Goals of Qualitative Inquiry

- Describe the process by which parents sought mental health services for their children, including their interactions with clinicians
- Describe providers' perspective on the delivery of mental health care to children

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Qualitative Inquiry Methods

- **Stage 1: Parents (n=7)***
    - Face-to-face and semi-structured
    - 2 interviews with the same person over 1 month.
    - Audio-recorded and transcribed, and hand-written field notes
- **Stage 2: Providers (n=7)**
    - 1 semi-structured interview.
    - Audio-recorded and transcribed, and hand-written field notes
- **Stage 3: Parent Focus Group (n=4)**
    - Discussed emergent themes from interviews
    - Audio-recorded and transcribed and observations

*Note: Only 7 out of the 10 original participants gave permission to publish data

Ongoing Analysis

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Sample: Parent/Caregivers

- Recruitment
  - 2 family advocacy organizations
    - *Maryland Coalition of Families for Children's Mental Health*
    - *NAMI – Metro Baltimore*
- Eligibility
  - Parent or Caregiver of school-age child who was currently receiving or had received mental health services
- Parent/caregiver sample
  - Middle-aged, Caucasian, married, biological parents
  - Mainly mothers/female caregivers
- Children
  - 14 years old (mean age), majority boys, bipolar most common disorder, most children had more than one disorder.
- **Institutional Review Board Approval** from Johns Hopkins Bloomberg School of Public Health Committee on Human Research and Johns Hopkins Medicine

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Sample: Providers

- **Recruitment**
  - Professional contacts
  - Traditional mental health or school-mental health settings
- **Eligibility**
  - Treated and managed care for children with a mental illness
- **Provider sample**
  - 7 providers
  - Child psychiatrists (3), psychologist (1), licensed counselor (1), social workers (2)
  - Majority female, early/middle aged (25-50 yrs)
  - Majority >10 years in practice
- **Institutional Review Board Approval** from Johns Hopkins Bloomberg School of Public Health Committee on Human Research and Johns Hopkins Medicine

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Analysis: Grounded Theory Approach

- **Review** transcriptions and field notes and **Code** data
  - Key ideas and phrases
  - Critical incidents/moments
- **Compare** codes within parent/caregiver and provider interviews
  - Identify similarities/differences across interviews and between providers and parent/caregivers
  - Use of logic diagrams and matrices
- **Identify** emergent themes
  - The meanings that individuals ascribe to their experiences
- **Assess credibility** of initial findings (Member checking and triangulation of data sources and methods)

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Results: Key Theme

- *Quest for Knowledge*
  - The family's search to find a 'name' for their child's illness

  - Information seeking process defined by:
    - *What prompted families to search for this information?*
    - *How did families search for information?*
    - *Why was this information important?*
    - *How did it help?*
    - *What meaning did clinicians ascribe to a diagnosis?*

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What prompted families to search for this information?

- Awareness of their child's behaviors/moods as not being "normal"
- Need to make sense of their experiences and learn more about their child's condition
- Frustration obtaining information or accessing available services and resources for their children

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"The early signs were there but no one hands you a book in the beginning when you have a child."

- Delayed recognition of their child's mental health problems:
  - Parents' uncertainty distinguishing between normal and abnormal behavior
  - Provider ability to recognize and diagnose problem
    - Provider-Parent communication
  - Entry to mental health care through:
    - School/day care problems
    - Severe symptoms

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Awareness of a problem

"I think the hardest thing about getting all my kids treatment was that they didn't get it soon enough… and whereas my pediatrician did refer me to a psychologist, it took a long [emphasis] time to get to the psychiatrist….There's no real communication… I wasn't really giving them the amount of information they needed to figure out what was going on because they weren't asking me the kinds of questions that would elicit it."

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Need to gather information

"I can't do anything without knowledge…you know it's like working in a dark room trying to find a thread in a dark room. No matter how much searching you do you're not going to be able to help the person who needs help."

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How did families search for information?

- Consumer Advocacy Organizations
  - Educational Workshops
- Reading books and the Internet
- Seeking out multiple providers
  - Using information given by one provider to confront another
- Social networks
  - Other parents of children with mental health problems

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Why was this information important? How did it help?

- Negotiate with Service System and Providers
  - Informs type of treatment
  - Increases access to services
- Helps Families Cope
  - Promotes empathy and acceptance
  - Strengthens parental role
  - Confront stigma and labeling

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Indicating Particular Treatment

"I read about bipolar I said this was X [daughter] inside and out…it was finally even before she even went into the hospital, I said to the doctor, I think she needs to be on lithium and the doctor said, I think you're right. And we put her on lithium….Lithium took a long time, but about two years to improve her behavior noticeably to where she was not like going off every, you know, couple of times a day, raging."

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Access to services

"He fits everything. He's got the criteria. Give him the name, give him the diagnosis, give him the help he needs. I said please write it up because I have to go in for an I.E.P. meeting the next week… And with that information they changed his diagnosis from 04 to 14, which is autism."

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Empathy and acceptance

"I feel especially, in mental illness, um, the characteristics a person has often are so distracting from [what] they truly have to offer, and still have to offer if you can wade through the symptoms, and I think being able to recognize that and try and help a person who has mental illness be the best that they can be or cultivate the strength that they have can help you appreciate many of the more subtle strengths that everyone has."

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Attribution and role as a parent

"The one thing is that I realized that my daughter, especially, and well all my kids, that their behavior was not purposeful …I can adjust how it [behavior] affects me but I have to accept that there are certain things that I really just can't control…And being able to let those things go is really difficult because you have an expectation of yourself as a parent…and its hard to accept that you can't fix it."

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Stigma and labeling

"I don't think its [anti-labeling] helpful. I don't think its helpful in the school setting either. I had this foster son who was very, very ADD. I couldn't get them to say that at school because they didn't want to label him quote unquote and I said yeah, 'if you don't have to label him, you don't have to help him.' So if he's not labeled…this is the nature of our system, if he's not labeled, he is not going to get the help he needs."

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Provider Perspective

■ Meaning of diagnosis is ambiguous:
- ■ Complexities associated with making an accurate diagnosis in children
- ■ Diagnosis is only one piece of treatment plan formulation
- ■ Communication of Diagnosis based upon intensity of treatment and nature of problem

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Provider Perspective

Communicating diagnosis based upon the intensity of treatment

"if the kid's going to be on medication…. The diagnoses will be talked with the parent in terms of medicine…the disorders that require medication….involve a lot more education about the specific disorders"

One provider [psychologist] explained that she did not provide parents with a diagnosis because this does not relate to how she treats mental illness. Her approach to treatment is focused on alleviating the symptoms, not the diagnosis.

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Provider Perspective

■ Focus on Managing Child's Mental Health Problems
- ■ Skills-based approach

■ Psycho-education
- ■ Doesn't necessarily consist of communicating diagnosis
- ■ Possible differences between academic vs. community based providers

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Provider Perspective

Providing families with skills to manage their child's problems

"I'm very much kind of skills-focused, so I think that most of the things that I talk with moms and dads about are skills that they have to learn how to do."---Provider

"As a parent, you are not equipped to manage severe mental illness, and so you don't know what to do…they'd [mental health clinicians] give you strategies that you'd never think of because you keep thinking that you are dealing with someone who'll stop doing it because you've told them to but they aren't going to."---Parent
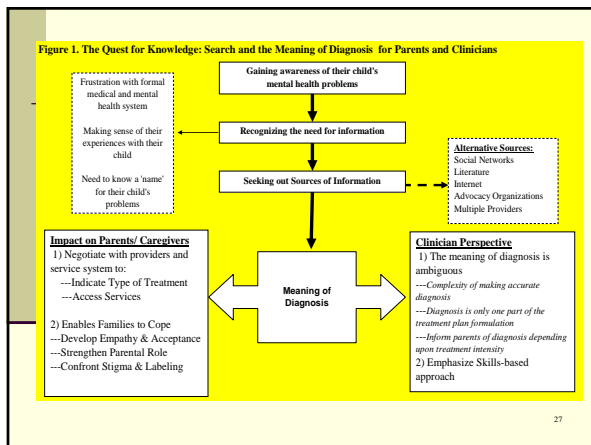
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Provider Perspective

Demystifying the problem

"I also spend a lot of time educating them about the illness. Trying to help parents determine what is child's illness vs. what is normal development vs. what is it, anything, they have done to contribute. BECAUSE they do want to know, they want to know if they have done something wrong."—Academically affiliated provider

"I also think that often times perhaps we don't educate parents well enough or they aren't educated well enough. Parents come in and say, 'Can you please fix my child and how many weeks do you think it will take?'—Former clinician, administrator

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Figure 1. The Quest for Knowledge: Search and the Meaning of Diagnosis for Parents and Clinicians

Frustration with formal medical and mental health system

Making sense of their experiences with their child

Need to know a 'name' for their child's problems

Gaining awareness of their child's mental health problems

Recognizing the need for information

Seeking out Sources of Information

Alternative Sources:
Social Networks
Literature
Internet
Advocacy Organizations
Multiple Providers

Meaning of Diagnosis

Impact on Parents/ Caregivers
1) Negotiate with providers and service system to:
---Indicate Type of Treatment
---Access Services

2) Enables Families to Cope
---Develop Empathy & Acceptance
---Strengthen Parental Role
---Confront Stigma & Labeling

Clinician Perspective
1) The meaning of diagnosis is ambiguous
---*Complexity of making accurate diagnosis*
---*Diagnosis is only one part of the treatment plan formulation*
---*Inform parents of diagnosis depending upon treatment intensity*
2) Emphasize Skills-based approach

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Implications for Children's Mental Health Services

- Family-Provider communication around issues of diagnosis
  - Importance of consumer advocacy organizations to educate family members
  - Psycho-education that includes discussion of diagnosis as part of treatment process
- Future Directions
  - Barriers to psycho-education: community based providers vs. academically affiliated providers
  - How do alternative sources of information supplement or substitute for traditional providers? 28

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