Qualitative Research in Health Services for Children with Chronic Health Conditions/Disabilities and their Families: the Continuity of Care Study

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10 January 2013 @ Sunny Hill

Researching non-categorically defined populations

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Presentation Outline

- Qualitative research: Overview
- Continuity of Care Study
- Qualitative research: Closing reflections

Qualitative Research: Overview

'Qualitative methods'

Key characteristics of qualitative research:

1. Study of things in the social world and their meaning for people

2. Nature of the data

3. Gather data in natural settings

Qualitative Research: Overview

Traditional foci

Qualitative Research: Overview

Qualitative research in health care

- What questions are we asking?

Qualitative Research: Overview

Qualitative methods and data

Qualitative Research: Overview

Tensions between qualitative and quantitative approaches

Qualitative-quantitative tensions

Qualitative Research: Overview

How qualitative research proceeds:
- research questions and goals
- methodology
- obtain data
- analyze and interpret data
- draw conclusions

Continuity of Care Study

Continuity of care –

connectedness of a patient (client)'s

care over time

across settings

across providers

Continuity of Care Study

Continuity of care –

relevance in childhood disabilities and rehabilitation

Continuity of Care Study

Literature review

- Academic and service provider perspectives

- In relation to adult patient/client groups

- Quite 'medical'
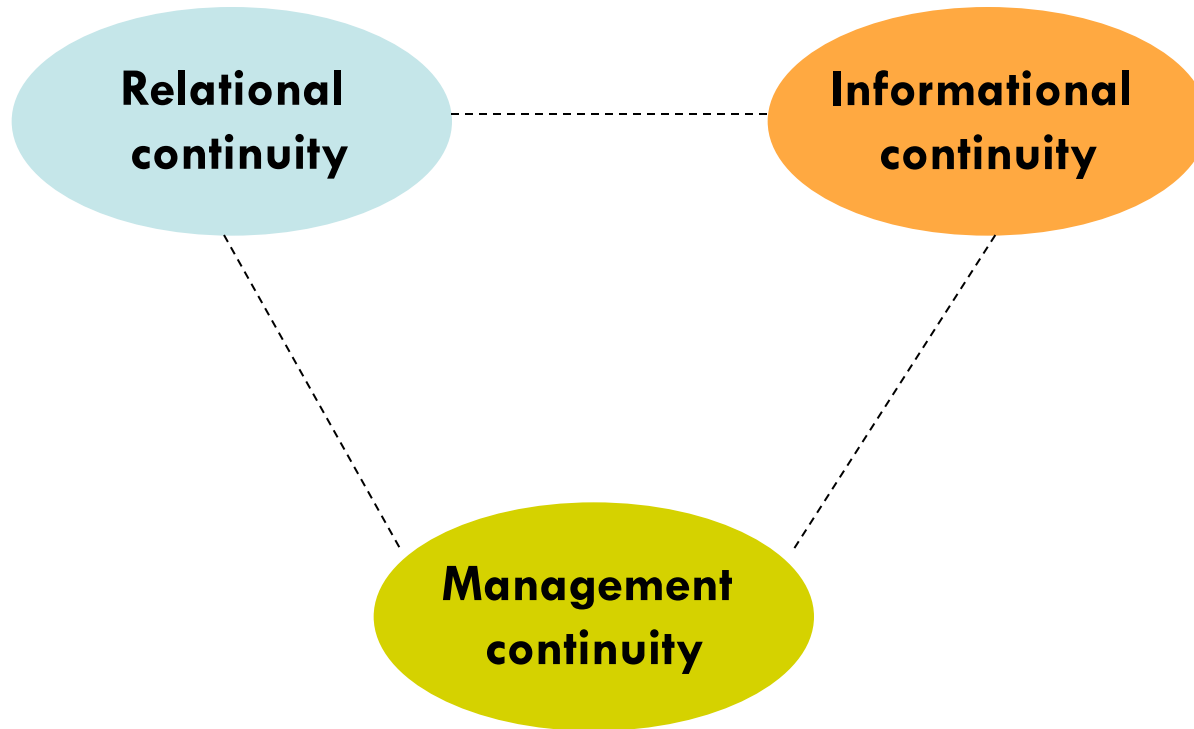
Continuity of Care Study

Key definitional elements

- an aspect of care experienced by persons receiving care, for services received over time;

- it involves the patient's ("client's") experience of consistency, smoothness, and coordination in care

- it relates to how patients/clients experience integration of services and coordination among providers

Reid, Haggerty, McKendry. CHSRF 2002; Haggerty, Reid et al *BMJ* 2003

Continuity of Care Study

Three main dimensions

Reid et al, CHSRF 2002; Haggerty et al, BMJ 2003

Continuity of Care Study

Continuity of care literature review

Continuity of Care Study

Research questions/goals

- How do parents of children with chronic conditions <u>perceive</u> continuity in the care they have received?

- How do their perceptions <u>align</u> with those in academic literature?

- What are the <u>salient factors</u> in continuity, for them?

How should we address these questions?

Qualitative Research!

Continuity of Care Study: method

Recruitment

In-depth
interviews

Transcription of data

Coding and analysis
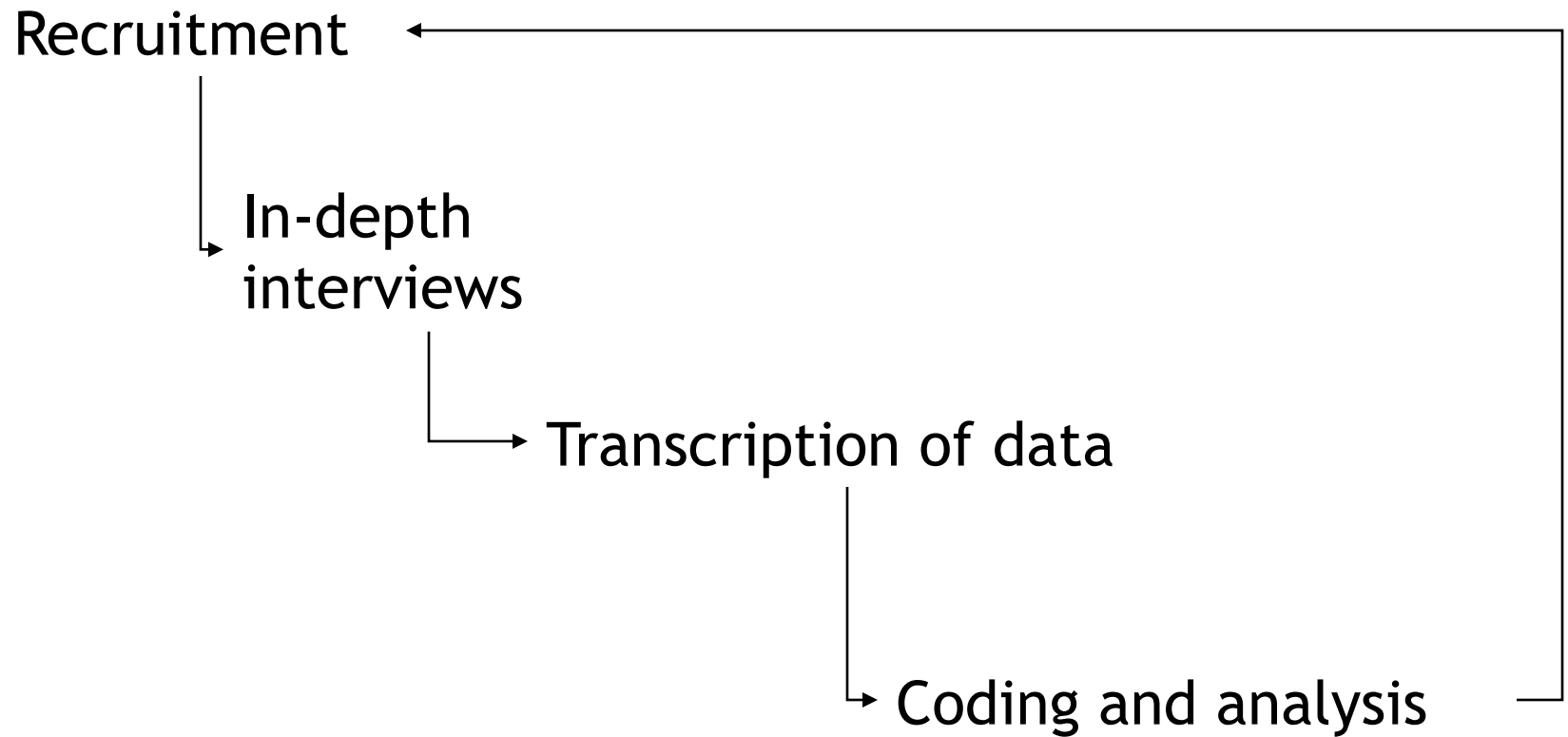
Continuity of Care Study

Selected conditions

- Spina bifida
- Down syndrome
- Attention-deficit/hyperactivity disorder (ADHD)
- Duchenne muscular dystrophy (DMD)
- Cystic fibrosis

Continuity of Care Study

Participants and their recruitment

➢ Hospital clinics
➢ Community sources

Continuity of Care Study: participants

Table: Characteristics of study participants

Interview participants (n = 47)	Mother only	26
	Father only	2
	Both parents (or grandparents)	19
Participants' health region of residence[*]	Interior	7
	Fraser	19
	Vancouver Coastal	8
	Vancouver Island	10
	Northern	3
Children's diagnosed health conditions	Cystic fibrosis	7
	Spina bifida	9
	Down syndrome	11
	Duchenne muscular dystrophy	9
	Attention-deficit/hyperactivity disorder	11
Age of children (years)	median (range)	9 (5-13)
Sex of children	Male:female	30:17

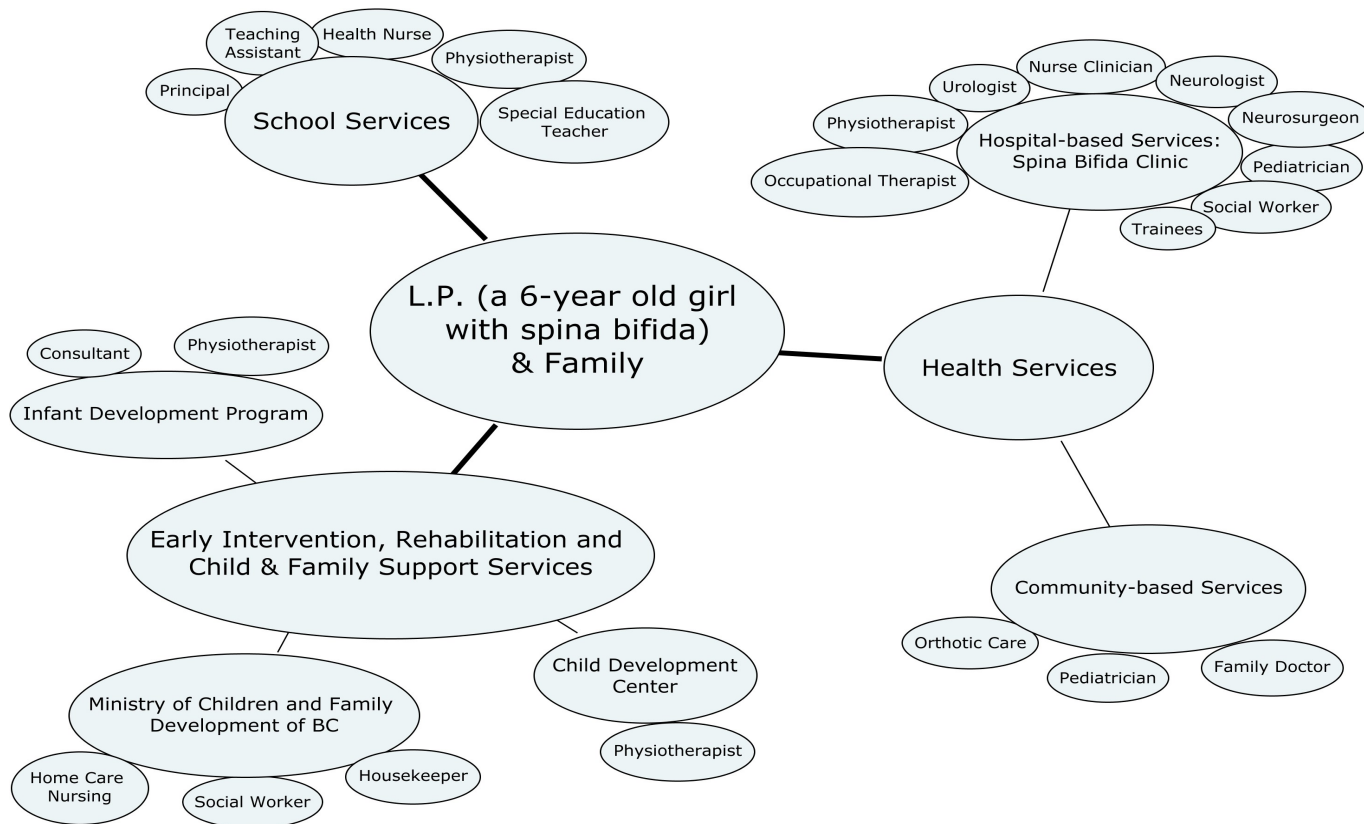[*]British Columbia is divided into five regional health authorities

Continuity of Care Study

Obtaining data

Interviews

- aiming for a spontaneous narrative about all their service providers, over time

Continuity of Care Study

School Services
- Teaching Assistant
- Health Nurse
- Physiotherapist
- Principal
- Special Education Teacher

Hospital-based Services: Spina Bifida Clinic
- Nurse Clinician
- Urologist
- Neurologist
- Neurosurgeon
- Physiotherapist
- Pediatrician
- Occupational Therapist
- Social Worker
- Trainees

L.P. (a 6-year old girl with spina bifida) & Family

Infant Development Program
- Consultant
- Physiotherapist

Health Services

Early Intervention, Rehabilitation and Child & Family Support Services

Community-based Services
- Orthotic Care
- Pediatrician
- Family Doctor

Ministry of Children and Family Development of BC
- Home Care Nursing
- Social Worker
- Housekeeper

Child Development Center
- Physiotherapist

Notes: Interconnections among service providers are not shown.

Continuity of Care Study

Analyzing data

- Software

- Coding and analysis
    - *I. Interim stage*
    - *II. Development of comprehensive coding scheme*

- Combined methods approach
    - inductive – deductive
    - "framework approach"
    - iterative

Continuity of Care Study

Findings: Six overlapping themes

1. Relational and informational continuity and their significance
2. Continuity and communication
3. Management continuity: seamlessness versus compartmentalization
4. Parents working to ensure continuity
5. Parents limiting continuity
6. Systemic and organizational barriers to continuity

Continuity of Care Study

Theme 1. Relational and informational continuity and their significance

- – "Knowing the child"

- – Knowing the child through relational and informational continuity

- – Relational and informational continuity pertains to <u>all</u> service providers

Relational continuity and knowing the child

"He [the orthotist] knows her. He knows her body, he knows how she moves. He knows how the bones are growing. He has seen her since she was born and followed her."

– parent of a child with spina bifida

"They (the teaching and support staff at school) know what's going on. They know the history, and they're experienced with the history. They don't just go by hearsay or records or things on paper. They know interpersonally what makes this person tick."

- father of a boy with ADHD and other behavioral difficulties

Continuity of Care Study

Theme 2. Continuity and communication

- – Communication—integral to positive experiences of continuity

- – Parents described close and reciprocal links among communication, relationship-building, and continuity of care

Continuity of Care Study

Communication

"The teachers would communicate with each other. I find in the lower grades when you have a child with special needs, when they were changing classes, the teacher would say, you know, you're getting Frank next year …. That worked really good. When you get into middle school, they have three different teachers … [and] the communication gets dropped."

- The parents of a boy with ADHD:

Continuity of Care Study

Theme 3. Management continuity: seamlessness versus compartmentalization

- – Contrasts between management continuity *within* a particular setting or service sector, and continuity *across* settings and sectors

Continuity of Care Study

Management continuity

- Poor linkage between the child's school program and medical services

  "Luke has an IEP, and it's strictly for his education, but there's no medical [component] included in that. It's almost separated, like … the behavior stuff is separate from the medical."

  - Parent of a child with Down syndrome and medical, learning, and behavioral challenges

Continuity of Care Study

Management continuity

- Geography

  "There's a crease down the middle of the paper and I feel this half [the clinic professionals in Vancouver] deals really well with each other, and this half [the people who work in the child's home town] deals really well with each other..."

  "You could almost call the crease a wall between the two."

  - Parents of a child with cystic fibrosis

Continuity of Care Study

Management continuity

- Constricted outlook (providers)

"For her [the child, in the eyes of the clinicians], it's just her medical care. Nothing to do with her emotional care, her quality of life."

- Parent of a child with spina bifida:

Continuity of Care Study

Management continuity

- Not being provided with sufficient information to address the range of needs

    - *"I think the individual health care workers do a good job. I mean, they do their work in their particular area and there's nobody really coordinating their work together. I see it as **all the other stuff** [social services and supports] that goes along with it that makes it all complicated and difficult."* (06DS)

    - *"Not only are you dealing with your child, you're dealing with the disease. You're dealing with the frustration of trying to get some kind of help, guidance, expert advice, and it's like two big jobs. You're finding out as much as you can about the disease and looking after your family, but you're also having to search, in all these different areas, for help."* (07DMD)

Continuity of Care Study

Theme 4. Parents working to ensure continuity
- A conduit between providers and settings

Continuity of Care Study

Theme 5. Parents limiting continuity
- – Sometimes prefer to have some constraints on the flow of information, or to regulate the flow of information between settings and providers

Continuity of Care Study

Theme 6. Systemic and organizational barriers to continuity

The policy environment:
- – Ageing out of services
- – Overlapping and conflicting organizational mandates
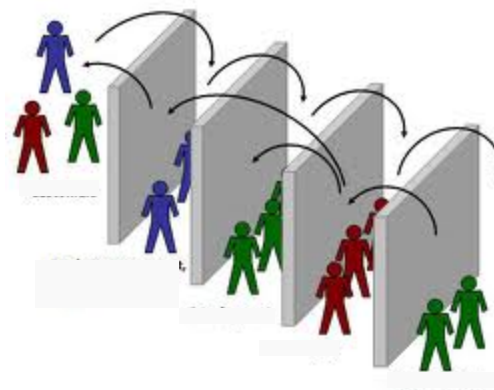
Grandmother of a boy with ADHD and learning problems:

"My biggest complaint about all of the resources is that they don't talk to each other. They truly don't talk to each other…And, every time, even if there's a worker who changes, you have to start right from the very, very beginning …"

Grandfather : *"The funding for the worker was coming from one place, and the funding for the daycare was coming from another place, and that was not coordinated well at all."*

Continuity of Care Study

Conclusions

- Existing academic concepts of relational, informational and management continuity were all discernable in parents' narratives.

- A thorough knowledge of the child on the part of service providers emerged as extremely important to parents (underpinned by continuity of personal relationships; also by written information.

- Notions of continuity extend to the full range of service providers these children and families need to achieve optimal health status

  ("continuity of services").

Continuity of Care Study

Conclusions

- Communication among providers was seen as integral to perceived continuity.

- <u>Compartmentalization of services</u> and information led to parents assuming a necessary, though at times, uncomfortable, coordinating role.

- <u>Barriers</u> to "seamless" management and continuity: geographic factors, institutional structures and practices, provider attitudes, and, on occasion, parent preferences and judgments.

Continuity of Care Study

Implications

- ✓ Add perspectives to the understanding of continuity of care within children's health care.

- ✓ Relevant to contemporary initiatives to improve services to children with special health care needs.

- ✓ Relevant to future research directions.

Qualitative Research: Final Reflections

- Powerful

- Accessible

- Deceptively simple

Research Team

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