

Coordinating care for children with special health care needs: What do parents and nurses do and what difference does it make?

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Objectives

Identify the aims and methods used in the *Family-Nurse Care Coordination Partnership Study*

Describe care coordination functions performed by nurses and parents of children with special health care needs

Identify the predisposing, enabling, and need determinants of nursing care coordination.

Discuss implications of results

Purpose

Family-Nurse Care Coordination Partnership Study

Improve care coordination services to families of children with special health care needs using a community-based participatory research (CBPR) approach that incorporates the expertise of parents, nurses, researchers, and related partners.

Community-based participatory research

Collaborative approach to research

**Participants & partners (Ø subjects)
have expertise, insight**

**Empowerment oriented – share \$,
decision-making, increase capacity**

**Findings used to improve conditions
through social action**

Viswanathan M, et al. (2004, July). *Participatory research: Assessing the evidence*. Evidence Report/Technology Assessment No. 99 (Prepared by RTI–University of North Carolina Evidence-based Practice Center under Contract No. 290-02-0016). AHRQ Pub 04-E022-2. Rockville, MD: Agency for Healthcare Research & Quality.

7 Parents



15 Nurse Coordinators



8 Research Staff

Overall Aims

- 1. Explore family and nurse experience with coordinating care & benefits to families.**
2. Develop a family-nurse partnered care coordination intervention that will teach families to navigate systems of care and teach nurses to better support families.
3. Deliver our intervention to a sample of families through trained peer-parents with the support of nurses; evaluate.

Children with special needs

Children "...who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally."

p. 138

McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P. W. et al. (1998). A new definition of children with special health care needs. *Pediatrics*, 102, 137-140.

Consequently...families

- **have greater care giving responsibilities than do families of children, generally**
- **navigate multiple services systems to identify & obtain services and assure communication among providers**
- **access “coordination” fortuitously**

Care Coordination

Care coordination is the process of arranging and integrating the delivery of health and related services across providers and service systems, over time, for families and their children with special health care needs.

An IOM cross-cutting priority to improve health care quality.

Kruger, B. J. (2004). Care Coordination. In P. Jackson Allen & J. A. Vessey (Eds.), *Primary care of the child with a chronic condition*, (4th ed., pp. 102-119). St. Louis, MO: Mosby

Coordination Literature

Peds & Family Nsg

4 decades well-reviewed research

Knafl, et al

↑ Theory building
Focus inside
child/family

≠ interface w/
systems

HSR – Utilization

Less likely to use
coordination:
Black, older age,
large families

Medical ≠ Nursing

CYSHCN & System

Limited #, methodological

Family & system interface

Brooten, et al – outcomes
APN model

**Coordination not defined, ? link btw process-outcomes,
Missing parent perspective, limits intervention development**

Research Aim #1

**What do parents/caregivers do
to coordinate care,**

**What do nurses do to help,
and how do parents/caregivers
benefit?**

Mixed-Methods Exploratory

Agency data, telephone survey &

In-home interviews with caregivers

CBPR Team identified

Questions for survey and interview

Nurse coordination functions

Parent coordination functions

Potential benefits of care coordination

Conceptual Framework

- **The Access to Health Care Utilization (Andersen) used in health services research and policy for > 30 yrs**
- **Utilization is generally captured in household survey data**
- **Access is whether services are actually used by the people who need them**
- **Guides organization of variables**

Child & Family Characteristics				Use Coordination		Outcomes
Predis'ing	Enabling	Need		Have a nurse		Benefits
<i>Child</i> *Age Sex *Race/ethnic	<i>Child</i> *Type service used (home, health, support, therapy, school, equipment) *# different services used # years Title V	<i>Child</i> *Co-morbidity *Health status *Unmet need, type of service *# unmet needs		-Contact freq -Type nurse -Comfort, medical -Comfort, non-medical -Type ways helps -# ways helps -Work as team		Caregivers Confidence w/ Title V Satisfaction Get Info they want Help parent help child
<i>Family</i> *Size Education Residence in same area	<i>Family</i> Income	<i>Family</i> *Severe \$ *Employ impact		Parent # ways coordinate Hrs/wk coordinate		Save time Less stress

Access to Utilization Framework (Andersen)

* Indicators of (medical) coordination significant for predicting use in pop studies

Exploration of new variables

Sample Selection

Telephone Survey

Random sample children (of 2,001) in Title V

Nurse care coordinator with large non-categorical caseloads (200+) vs small / specialized

In-home Interview

Selected to represent a broad range of use of services, need for services, and use of coordination.

Caregiver Respondents

	Survey	Interviews
Moms	334 (79%)	23
Dads	29 (7%)	3
Grandparents	40 (9.5%)	4
Relatives	19 (4.5%)	0
N=	422 (100%)	30

Results: Survey Sample, *predisposing*

Child

Gender	Fem 44.1% (n=186)	Male 55.9% (n=236)
Race/ethn	White 51.9% (n=219)	Black 34.8% (n=147)
	Hispanic 5.69% (n=24)	Other 7.58% (n=32)
Age	Mean/Median = 11 years, SD 5.09	

Family

Residence	≤10 yrs 15% (n=106)	11+ yrs 75% (n=316)
Education	< HS 14.7% (n=62)	HS/GED 37.3% (n=158)
	Some Coll 34.2% (n=144)	College+ 13.8% (n=58)
Size	Mean/Median = 4 persons, SD 1.6	
Language	English 96%	Spanish 2% Other 2%

Results: Survey Sample, *enabling*

Child

Type service used	95% Medical	50% Dental
In past 12 months	45% Therapy	44% Educ
	40% Equip	21% MH
	19% Support	12% Home

services used (0-8) Mean/Median, 3, SD 1.6

yrs in agency (0-20) Mean/Median, 5, SD 4.6

Family

Income	Median \$25,000
	Range 0-170 ⁰⁰⁰ , Msg: 130 (31%)
48% ≤\$24 ⁰⁰⁰	42% \$25-49 ⁰⁰⁰ 10% ≥\$50 ⁰⁰⁰

Results: Survey Sample, *need*

Child

Health status	Ex/vg	39.3% (n=166)
	Good	39.1% (n=165)
	Fair/poor	21.6% (n=91)
Unmet need, type	18% Dental	8% Therapy
In past 12 months	≤6% All others	
# unmet needs	Mean/Median,	0.57, SD 1.07
# co-morbidities	Mean/Median,	2, SD 0.84

Family

Severe \$ impact	34%	(n=143)
Employment impact	56%	(n=236)

<i>Ways caregiver coordinates</i>	<i>n=422</i>	<i>%</i>	<i>Didn't Need %</i>
<i>Information</i>			
Find providers	386	91.69	2.61
Communicate w/ providers	405	96.43	1.43
<i>Facilitate access</i>			
Paperwork, applications	366	87.14	3.81
Make appointments	413	98.10	
<i>Funding</i>			
Find \$ to pay for services	332	79.62	
<i>Teach</i>			
Child's condition	371	88.54	2.39
<i>Anticipate future</i>			
Plan future and ed needs	393	94.02	2.39

Total Ways “coordinates” Median: 6.3, Mean: 7, SD 1.78, Range 0-7

Hours / week coordinating care, median = 4, mean=11, SD 23.7, ** “24/7”

Interview: Caregiver coordinates

- The caregiver “parents;” term coordination is jargon.
- Caregiver “stress,” marriage, sibs, \$.
- “Stubborn” their way through system.
Ask everyone / anyone, trial and error.
Search internet (70% on survey)
- Organize using planners, boxes, files, drawers
- Don’t know what a “care plan” is even though they are supposed to receive one annually
- Need help with school system and getting MD’s to listen to them

<i>Ways Nurse Helps, n=369</i>	Yes <i>n</i>	Yes %	Don't need %
<i>Information</i>			
Understand Title V	313	85.99	5.49
Find providers	265	72.80	10.71
Connect to parent support	91	25.00	34.62
<i>Assess, Plan, Monitor</i>			
Ask what you need	303	83.24	1.37
Listen to concerns	294	80.77	3.85
Check how you are doing	250	68.87	2.20
Help plan for future	129	35.44	19.78
<i>Fund</i>			
Understand insurance	249	68.78	10.77
Find \$ to pay for services	176	48.35	23.90

Ways Nurse Helps, n=369	Yes <i>n</i>	Yes %	Don't need %
<i>Teach</i>			
How to get services	225	61.98	12.95
Medications, treatment	212	58.24	24.45
Child's condition	205	56.32	24.18
<i>Facilitate access</i>			
Paperwork, applications	169	46.56	29.20
Make appointments	112	30.77	29.95
Arrange transportation	20	5.49	61.26
Accompany on visits	28	7.69	42.31

Only the 369 of respondents who said they “had a nurse” were asked these questions

ways nurse helps Median: 9, Mean: 8, SD 4.1, Range 0-16

<i>Characteristics of Nurse Coordination, n=369</i>	n	%
<i>Discuss medical needs</i> Very/Somewhat comfortable	227	89.59
<i>Discuss non-medical needs</i> Very/somewhat comfortable	294	80.76
<i>Work as team, nurse-parent</i> Strongly agree/Agree	293	80.49
<i>Frequency of contact</i> Very often/often	142	39

Only the 369 of respondents who said they “had a nurse” were asked these questions

Interview: Nurse Helps

- Some long term relationships; others disrupted by frequent nurse turn-over / agency re-assignment.
- Some parents independent; others willing for the nurse to take care of it all. Relationship is key.
- Caregivers call nurse for access to appointments, services, funding, information (like hurricane preparedness), support, & updating on child status.
- Want nurse to be a resource, available, initiate contact, be responsive, help anticipate needs, assure comprehensive care, provide support.

<i>Outcomes/Benefits</i>	<i>n</i>	%
<i>Satisfied with help from nurse</i>		
Very /Somewhat satisfied	317	87.1
<i>Benefits of Nurse</i>		
Get info needed	304	83.75
Feel less stressed	245	67.31
Save me time	236	64.84
Learn to do things for child	224	61.54

Only the 369 of respondents who said they “had a nurse” were asked these questions

benefits Median: 3.5, Mean: 2.77, SD 1.5, Range 0-4

Interview: Caregiver Benefits

- Emotional support: someone who cares, someone to talk to, who is there for me.
- Comfort, peace of mind, less stress, less worry, makes things easier
- Loss of nurse would impact child's quality of care, their finances, emotional support, perceived empowerment, a resource to call for help, or "leave me alone to fend for myself."
- 50% could not articulate benefit, 20% reported no negative impact if they lost their nurse.
- Frequency of interaction / relationship important

What predisposing, enabling, or need factors, with nurse characteristics, predict how often caregiver uses nurse coordinator?

<i>Logistic Regression</i>	OR	[95% CI]	<i>p</i>
# services used	1.2	[1.05-1.42]	0.01
# services needed	0.74	[0.57-0.97]	0.03
Type nurse <i>primary care vs phone</i>	3.2	[1.75-5.98]	0.0002

Covariates not significant: race, health status, education, employment impact, severe \$ need

n=349 complete cases of those who had a nurse

Which nurse characteristics, with predisposing, enabling and need factors, predict caregiver satisfaction?

<i>Logistic Regression</i>	OR	[95% CI]	<i>p</i>
Work well as team	8.45	[4.03-17.07]	0.0001
Comfort w/ medical	4.22	[1.63-10.94]	0.003
# ways nurse helps	1.29	[1.17-1.42]	0.0001

Covariates not significant: yrs. in agency, comfort w/ non-medical, type nurse, education, race, health status, #total services used, employment impact, severe \$ need

n=339 complete cases of those who had a nurse

Discussion

- Use of combined methods – randomized survey and interviews – allowed breadth and depth exploration
- Provides information about what parents do to “coordinate” in spite of having an assigned coordinator, how they benefit, and what they want.
- Coordination is for the caregiver; child is agency client; and is a family intervention, implies need to assess caregivers
- Nurse coordination not associated with disparities (age, race/ethnicity) as in medical coordination

Limitations

Cross-sectional, non-causal

Non-categorical vs specialized conditions

Agency data (co-morbidities) may be incomplete

Based on self-report, however, recall bias reported to be minimal

Pless CE & Pless B. (1995). How well they remember: the accuracy of parental reports. *Arch Pediatr Adolesc Med.* 149, 553–558.

No intent to evaluate quality

Generalizable only to agency population

Survey tool not pilot tested

Implications

Theory

Concepts: stress, partnering, relationship building, self-directed care, role negotiation

Research

Matching caregiver and nurse expectations, balancing autonomy/independence with appropriate level of caregiver support

Practice & Policy / social action

Building relationships requires face-to-face contact, assessment of family strengths and concerns, lower caseloads

Information used...

1. Parent Survey, Interviews +
2. Nurse focus groups to explore family-centered care practice +
3. 10 month CBPR study team exploration: family-centered, partnering, coordination, compliance, roles

To develop an intervention that helps caregivers navigate the system and nurses to work with families

Co-Investigators

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