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Mothers of Children with Special Health Care Needs: Documenting the Experience of Their Children's Care in the School Setting

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Abstract

The numbers of children with special health care needs (CSHCN) have increased in schools. This study was conducted to document mothers' experiences of the care their CSHCN receive across health care and educational settings. Data were collected during standardized, open-ended, one-on-one interviews with 10 mothers of CSHCN in urban, suburban, and rural areas in a Midwestern state. Interviews were transcribed and content analysis revealed five themes: (a) communication, (b) educational system issues, (c) mother as a caregiver and expert, (d) navigating the system, and (e) strategies and coping. Describing and understanding experiences of mothers of CSHCN is important to developing appropriate supportive interventions.

Keywords

children with special health care needs; medically fragile; school nursing; family psychosocial factors; child health services

INTRODUCTION

As a result of medical advances and federal educational mandates, the number of children with special health care needs (CSHCN) has increased dramatically in schools. CSHCN are those children "who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally" (McPherson et al., 1998, p.138). It is estimated that almost 14% of children less than 18 years of age in the United States, or about 10.2 million children, have special health care needs. Of these, 60% have their daily activities affected by their health condition (U.S. Department of Health and Human Services, 2008). These children often require care that involves multiple medical and educational services. *Healthy People 2010* objectives for improving health (U.S. Department of Health and Human Services, 2000) include the recommendation that CSHCN receive care through a comprehensive, community-based, coordinated, and family-centered service system. Despite this recommendation, however, the coordination of care that CSHCN receive remains fragmented across community, health care, and educational systems (U.S. Department of Health and Human Services, 2008).

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Parents of CSHCN often have greater child-raising responsibilities than those of parents of typically developing children (Ray, 2002). Parents participate on educational teams, advocate for their children, and become decisional experts regarding the health care of their children. They may have to perform complex technical medical procedures and make decisions about symptoms and when they constitute an emergency. Parents also attempt to compensate when their children are unable to achieve typical developmental achievements. They create social opportunities for their children, navigate the health care and educational systems, and search out needed services (Ray, 2002). The burden on mothers is especially heavy, with almost 30% reporting having to reduce employment or stop employment altogether to take care of their children (U.S. Department of Health and Human Services, 2008). Although the burden is heavy and mothers would benefit from supportive health care, school, and community partnerships, coordination of support is limited.

The health care needs of CSHCN are often challenging to school personnel. School districts are responsible for providing free, appropriate public education to all children in the least restrictive environment (Individuals With Disabilities Education Improvement Act of 2004). Although a public education for CSHCN is mandated by law, the amount, type, and quality of care they receive in school is not well defined, despite evidence that the quality of care a CSHCN receives in school may affect school attendance and performance (Ireys, Salkever, Kolodner, & Bijur, 1996). School personnel often report feeling inadequately prepared to understand health and medical matters and how to handle related emergencies. Educators rely on parents and school nurses for information about how the health care needs should be met (Botcheva, Hill, Kane, Grites, & Huffman, 2004). Little research is available on mothers' experiences regarding the health care of their CSHCN while at school. Therefore, the aim of this study is to explore and describe mothers' experiences with the care and coordination of care of their CSHCN in the school setting.

REVIEW OF THE LITERATURE

Studies of parents of CSHCN have reported several commonly encountered phenomena in regard to their children's care in school. These include the parents' expressed need for communication and coordination between providers in the health care setting and those in the educational setting as well as issues involving educational resources and staff training.

COMMUNICATION AND COORDINATION

Kliebenstein and Broome (2000), in interviews with 21 parents of children who were returning to school with a chronic illness, found that parents felt resentful that they were expected to do all of the communicating with school personnel and that the health care staff did not communicate with the school. Lutenbacher and colleagues (2005) used focus groups to explore the challenges faced by 37 parents of CSHCN. They found that schools were a source of challenge. Parents identified a disconnect between services and a lack of communication among all those involved, including the primary care provider, specialists, therapists, teachers, and insurance companies. The parents expressed a need for a case coordinator between service systems such as health, school, and insurance services. In a longitudinal study of 124 parents and their perceptions of helpful and unhelpful types of support, Garwick, Patterson, Bennett, and Blum (1998) found that parents expressed comments about poor verbal and non-verbal communication among school providers similar to what they expressed regarding health care providers.

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EDUCATIONAL RESOURCES AND STAFFING

In focus groups with 31 parents of children with a variety of developmental disorders, Freedman and Boyer (2000) found that parents lacked an organized way of accessing the kind of support that they needed. The parents were concerned with the lack of knowledge, inexperience, and fears of school personnel in accommodating their children's needs in the school setting. They also expressed a need to have to fight for everything they had, even though there was no one to tell them how to do it.

In the study of Kliebenstein and Broome (2000), the parents also thought that when there was little communication from the school it was due to a lack of time and resources on the school's part. Although all the schools in the study had school nurses, the nurses were responsible for entire school districts. The parents expressed concern that their children would only be given attention if problems arose. Others thought that it was unreasonable for one nurse to be expected to provide adequate care across an entire school district.

Rehm and Rohr (2002) conducted a study of medically fragile and technology-dependent children. As part of the study, interviews were conducted with 11 parents. The parents found that it took months or years to understand their legal rights regarding educational services. Once realized, the parents expressed frustration with the need to have to maintain an ongoing vigilance to monitor their children's needs at school. Parents believed that identifying one person in the school to advocate for their child was crucial. If they could not identify someone within the school, they often resorted to using outside advocates or threatening legal action. Persistence was seen as important as parents dealt with situations where their children's needs were not being met.

In a phenomenological study of 12 mothers of children with type 1 diabetes mellitus in Taiwan, Lin and colleagues (2008) found that mothers were worried about the safety of their children at school. As a result they regularly contacted and interacted with the schools to ensure their requests were met and to educate school staff. Parents also expressed frustration with the amount of time, energy, and personal resources that were required to ensure that their child's needs were met in the school (Lutenbacher et al., 2005).

Garwick and colleagues (1998) asked 63 families for their recommendations for improving the care of their children with chronic illnesses. The parents reported that they wanted school personnel to be better informed about their children's needs. They found unsupportive behavior among school personnel, including the provision of inadequate services, insensitivity to the child's needs, lacking understanding about the child's condition, inadequate professional knowledge, and a lack of recognition of the child's problems and needs. Taken together, the literature indicates parents of CSHCN provide much of the coordination between providers in the health care setting and individuals in the educational setting. This was made difficult by the lack of communication between systems, the complexity of the educational and legal factors involved, and the time and energy required to ensure that needs were being met.

CONCEPTUAL FRAMEWORK

This study is part of an overall social marketing planning framework used by the author to develop an educational intervention for school nurses to prepare them to care for and to coordinate the care of CSHCN. The social marketing planning framework involves the use of commercial marketing techniques to change the behavior of a target population (Weinreich, 1999), by offering benefits they want, reducing barriers, and using persuasion to motivate their participation in the program (Kotler & Roberto, 1989). In this framework, all program decisions are based on consumer input. In this case, the consumer is the school nurse. Understanding the experiences of mothers of CSHCN with school nurses and the mother's perception of nursing

care in the schools will influence the goals of the program. A descriptive qualitative approach was used to explore and better understand (a) the type of care mothers want, (b) the type of care they receive, and (c) the barriers they encounter in the educational system.

METHOD

Participants

The participants were identified by the state coordinators of *Family Voices*, a family-directed national organization that advocates on behalf of CSHCN, from among the families with whom they work. The families all lived in an Upper-Midwest state. The staff of *Family Voices* made first contact with the family by telephone or e-mail. The study aimed to enroll 10 parents who care for a CSHCN. The number of participants recruited was based on previous studies and was anticipated to be adequate to reach saturation in thematic areas (Fisher, 2001).

The selection criteria were (a) the participant must be the parent of a CSHCN who is enrolled in a public school in grades kindergarten through 12, (b) the participant must speak English, and (c) the participant must be able to tolerate an hour-and-a-half interview. The staff of *Family Voices* contacted families so that there was an equal representation of rural and urban areas. Participants were paid US\$20.00 in cash for participating in the interview. Data were collected under a protocol approved by the university Health Sciences Institutional Review Board.

The data were gathered from 10 mothers of CSHCN whose children were enrolled in public school (grades K-12) at the time of the study. Families were contacted, and fathers and mothers were eligible. However, no fathers chose to participate. A noncategorical approach to the child's chronic condition was taken in this study. In this approach special needs are identified by the health consequences experienced by child, not specific diagnoses or disabilities. There is evidence that children with chronic conditions and their families experience similar phenomena such as psychological burden of the condition, responsibility for medical and nursing tasks, and disruption of family routines (Stein & Jessop, 1989). The chronic conditions of the children in this study, as well as the demographic characteristics of the mothers and children can be found in Table 1.

Procedures

One-on-one, in-depth, standardized interviews were conducted in the participant's home. The interviews were audio-recorded and varied from 1 to 2 hr in length. The interviewers were all bachelors-prepared registered nurses and graduate students in a masters level Pediatric Nurse Practitioner program. Before interviewing, they were trained in consent procedures, interview protocol, and interviewing techniques. After consent was obtained, parents were asked standardized, open-ended questions about life with CSHCN; the care and coordination of care received; the care received at school; their satisfaction with care; and their communication and involvement with school.

DATA ANALYSIS

All audio recordings of interviews were transcribed verbatim. A team consisting of nursing graduate and undergraduate students; human development and family studies undergraduate students; and nursing faculty was involved in the analysis of the data. The descriptive content analysis strategy was adapted from Hsieh and Shannon (2005). First, each team member independently read all of the interviews to acquire a sense of the whole. Next, the interview texts were read again to derive codes by highlighting phrases from the text that captured key thoughts or concepts. The team met, and the coding of the individual interviews was compared and discussed. Related codes were sorted into categories and categories combined into

overarching themes. Definitions were developed and exemplars were identified for each theme. Next, the research team validated the themes and established inter-coder reliabilities. Five two-person teams were formed. Each team was assigned 1 interview chosen at random from the original set of 10 and 1 that neither team member had previously coded. Each individual within a team independently read through their interview and assigned previously established themes to phrases. The teams met and the results were compared. The percentage of time that both members of the team agreed a phrase was associated with a particular theme was calculated (Table 2). Inter-coder agreement ranged from 82% to 94%. The numbers in Table 2 are coded phrases.

Trustworthiness

The trustworthiness of the analysis was established following the recommendations of Graneheim and Lundman (2004). Credibility, the confidence in how well the data and analysis address the study focus, was established by having participants with varying locations, resources, and CSHCN diagnoses, thus increasing the possibility of examining the research question from a variety of viewpoints (Graneheim & Lundman, 2004). Credibility was also increased by seeking agreement among team members on codes, categories, and themes. Dependability, the degree to which data interpretation changed over time, was addressed by verifying the accuracy of transcriptions of audio-taped interviews, using a semistructured interview guide to standardize questions, training data collectors in interviewing techniques, maintaining an open dialogue within the research team, and documenting analytic decisions. Transferability, the extent to which findings can be transferred to other settings or groups, was facilitated by a thorough description of the selection and characteristics of the participants, the data collection and analysis process, and presentation of findings along with quotations.

RESULTS

The results of this study describe mothers' experiences with the care and coordination of care of their CSHCN in schools. Five themes emerged: (a) communication with health care providers and schools was difficult; (b) school personnel were often not prepared for the challenges presented by CSHCN; (c) mothers, as the primary caregivers, saw themselves as the experts on their children and children's condition; (d) mothers struggle with navigating the educational and health care systems; and (e) mothers used various strategies to cope with the challenges presented by their children's condition.

Communication

Communication between systems and individuals was a common theme throughout the interviews. Mothers recognized the lack of communication between those in the health care setting and school setting. They expressed that it was often the mother who must do the coordination and that it was their responsibility to make those at school aware of the medical status of their children. One mother wonders exactly what was communicated between the school and clinic:

I don't feel that they communicate very well with the school. Um, they will fax over you know ... the information that needs to be signed for medications; they'll sign it and send it back. But I don't know exactly that they're really ... totally ... coordinating with them. It's like me coordinating in between the two

Educational Issues and School Personnel

The mothers had much to say about the care that their children received at school. They spoke of the roles of educators, paraprofessionals, and school nurses. There was some variation in the mothers' perceptions of the role of the school nurse. Some had no contact with a school

nurse. Others had limited contact with a school nurse but surmised that the nurses' part-time employment and/or broad responsibilities were at least partly responsible:

We never once saw a nurse. And it would have been nice to be seeing a nurse, in fact I requested a couple times, but she was always gone because she had 5 schools, you know? She was never there. I think she worked like 20 hours between 5 schools.

Other mothers found the services of the school nurse to be of help in

(a) establishing continuity of care

We've had the same school nurse since she went into Early Childhood ... so it's been nice from the very beginning and she was willing to go ... find all the release forms ... she read through [Name's] file and took copious notes. So she really had a sense at least medically of what [Name] has been through.

(b) improving communication

The nurse comes to all of her IEP [Individualized Educational Plan] meetings; it's always really professional and updated with information; that's always a component of our meetings. So everybody hears 'Oh, we saw ... Neurology and they changed her meds. Here's what the meds are; here's what some of the side effects might be, so keep your eyes open.' So they know what's going on.

(c) providing support to parents and educators

The nurse knows her ... and I think the teachers feel really supported by her [the nurse]. And if they've got questions, they can ask.

The participants recognized the disconnection between the health care and educational systems. They had children who needed a type of care in school that in the past had been provided in a health care setting. They were, however, sympathetic to the sometimes difficult position of the teachers and educational paraprofessionals in providing this care:

The teachers ...[sighs] I feel for the teachers. They come out ... thinking they were going to get a room full of kids [to teach] ... they end up being left with ... a room full of kids with ... significant health care needs.

Mother as Caregiver and Expert

All of the mothers indicated that they were "more than just a mom." Their role was not just parenting, but multidimensional. Each used the term "24/7" to indicate the level of intense, nonstop involvement they had with their children, for example:

Okay. I would say we probably spend ... I can't even estimate. It seems like my whole life focused around that. So, I don't know if I can quantify it in a number of hours in a day. It's 24/7. I don't think you get a break from that.

The mothers also indicated that they thought that their expertise needed to be recognized, but that this was not always the case:

I felt, as a parent, if I was going to throw an extra sandwich in her lunch box, I would not need a signature from the doctor. But, just because it's through the G-tube, you count it as a change in her medical procedure, and now I have to get a new signature. And I even tried having the form filled out to say "per parental instruction" and they still made me ... go back to the doctor and ... and it wasn't even that big of an inconvenience, as much as it was more of a slap in the face, and undermining my parental authority.

Navigating the System

Mothers also spoke of their creativity in navigating the health care and educational systems:

I heard the saying that they put parents on a treadmill. .. Oh, you have to be doing this, you have to be doing that ... you have to be doing this, you know, in order to feel effective; And you know what? [chuckles] They're right.

They also spoke of the time involved in simple and complex activities related to their children:

There are some weeks I don't get anything done. Very seriously ... you have reams of paper that you've got to read through ... and all the appointments that are part of that, making doctor's appointments ... But it's always something; all the way through, it's always that 'something' ... there's always a fire to put out.

Mothers' Strategies and Coping

Mothers spoke of overcoming adversity, and over time, reaching out and developing supports and strategies for coping with their children's needs and the ramifications of those needs in their lives. Three mothers spoke of the strategies they used in working with school and health care personnel:

... for me, it was extremely, extremely frustrating, because I'm college-educated ... I'm a writer, so I'm used to doing research. And we researched these things, and ... I learned to 'dumb-down' ... and then they could feel like super heroes.

You know, IEPs were good ... I brought cappuccino, and cookies, and we sat there and talked ... I gave them 3 goals each year to work towards, and everything they did ... was to include those 3 goals, you know, so they can remember? Teachers can't remember 25 goals for every kid so ... I set the tempo of it ... the teachers came in laughing and happy. I brought cappuccino and cookies for a reason. You catch more flies with sugar than you do with vinegar.

So even though I indicate passion when I'm talking about some of these situations, never think that I went in with that attitude, because I never did. I always went in with this "ask - care" attitude. Because if you do kiss somebody ..., [kiss the] doctor because they can move mountains for you.

Mothers also made a point to emphasize the joys and rewards involved in raising their CSHCN.

Yeah. I would have to say that if we had the choice to ... not have [Name] the way she is ... I wouldn't want her any other way. ... it's funny how sometimes it, it almost irritates me when people will say ... [Name] has Down syndrome, ... "Oh, I'm so sorry." And I'm like, "Well what are you sorry about?" [Chuckles] You know? We're lucky. ... we're just happy with who she is.

I think one of the things some have asked me is, about how it might be hard or stressful having a child with special needs. And I really don't think it's my child with special needs that causes the greatest stress. I think it's all these things that go along with it It is all these things we bump into, in the, the system and the society that make it hard.

... being a parent of a child with special needs can be really challenging and really rewarding. And that can put you to discover new strengths in yourself that you didn't know you had

Mothers in this study expressed concerns regarding the care of their CSHCN at school. Communication between the educational and health systems and between individuals was difficult. Mothers encountered challenges with educational issues and with educational

personnel. Not all had contact with school nurses, but those who did found the support helpful. The mothers indicated they became the experts and care coordinators for their CSHCN. They also spoke of strategies they used to cope with the challenges their children presented. Importantly, the mothers expressed the joy and rewards that are also part of parenting their children.

DISCUSSION

The Education for All Handicapped Children Act (Public Law 94–142) was enacted in 1975, assuring a free appropriate public education to all children with disabilities. Almost 35 years later, as evidenced by the results of this study and others (Lin et al., 2008; Lutenbacher et al., 2005; McPherson et al., 1998), schools still present barriers to CSHCN and their families. Five themes emerged in the analysis of the interview data in this study of mothers of CSHCN and their children's care at school. Mothers in this study reported that communication with health care providers and schools was difficult; school personnel were often not prepared for the challenges presented by CSHCN; mothers saw themselves as the primary caregivers and experts on their children and children's condition; and they used various strategies to cope with the challenges presented by their children's condition and to help them navigate the educational and health care systems.

Supporting Ray's (2002) findings, mothers in this study indicated that they were overwhelmed with coordinating care and advocating for their children. They did not experience easy communication between health and educational professionals; rather, they thought that they were the ones who acted as the liaison between the two systems. There was no apparent formal structure or system for the transfer of information or for care coordination. The mothers felt the burden of having to administrate, coordinate, and advocate for their children's health care. This burden extended beyond the health care system into the educational system where mothers fought for services for their children, becoming familiar with special education law and The Americans with Disabilities Act. Although this was seen as burdensome for all of the mothers in this study, those mothers who do not have the education or resources to fight for services are particularly in need of support.

In several cases, the mothers indicated that a school nurse was involved in the planning, coordination, and delivery of care. The nurse involvement was seen as improving communication, improving continuity of care, and providing support to teachers and parents. In other cases however, the mothers had no involvement with a school nurse, despite the complex needs of their CSHCN. Those who indicated no involvement with a school nurse were the parents who lived in the more rural areas. Because the state in which the study took place does not require school districts to have a school nurse, it is possible that these rural school districts either employed one nurse for an entire school district, consisting of multiple schools often miles apart, or did not employ a school nurse. Both circumstances would make it difficult or impossible for a school nurse to be effectively involved in the care of a CSHCN. Overall, even the mothers who had school nurse involvement did not necessarily view school nurses as potential sources of support. Lutenbacher and colleagues (2005) encountered a similar finding in their study of families caring for CSHCN. They found that parents who had experience with school nurses were unable to determine what relationship the nurse had with their children, or they described the nurse as another barrier.

The mothers in this study saw themselves as the experts on their children's care, as was seen in the study of Garwick, Kohrman, et al. (1998) on family recommendations to improve care. Families in that study placed a high value on being "heard" and thought that "parents are not listened to." Indeed, one mother in this study thought the school's actions to be "a slap in the face, undermining my parental authority." Mothers also became experts at navigating the health

care, educational, and insurance systems and used various strategies to accomplish their goal to obtain services for their children. Some of the strategies included “playing dumb” to placate school staff, bringing treats to IEP meetings, and using deferential behavior with doctors. Lutenbacher et al. (2005) found three major roles for parents of CSHCN: being an advocate or a “fighter” to “get what your child needs,” a guardian “to protect your child” from uninformed or incompetent professionals, and “to be an expert” about your children and their condition.

“Mothers also became experts at navigating the health care, educational, and insurance systems and used various strategies to accomplish their goal to obtain services for their children.”

There is evidence that there are factors that make any collaboration between educational and health care systems difficult (Poursanidou, Garner, & Watson, 2008). There is a lack of understanding on the part of both health care providers and educators regarding the other’s roles and responsibilities regarding CSHCN. The dual lack of understanding is not surprising given that the systems operate very differently and have very different missions. Both groups of professionals are working in systems where there is limited time and resources for liaison and educational systems have been perceived as unsupportive of CSHCN (Freedman & Boyer, 2000; Garwick, Patterson, et al., 1998; Rehm, 2002).

School nurses are in a position to provide care coordination to families (Lutenbacher et al., 2005), but they need to be adequately prepared to perform this role (Lindeke, Leonard, Presler, & Garwick, 2002). Evidence-based best practice elements that need to be in place for successful collaboration between health and educational systems include (a) the professionals in both need to have an understanding of, and respect for, each others roles and expertise, (b) the communication and information-sharing system between the two systems needs to be coordinated, and (c) joint trainings need to occur between the two (Poursanidou et al., 2008). There are successful programs in place that may serve as models for improving communication between systems and supporting CSHCN and their families. The Healthy Learner Model for chronic condition management (Erickson, Splett, Mullett, & Heiman, 2006) is an example of a comprehensive, integrated model that links schools, students, parents, health care, and other community providers. The model identifies elements for creating a comprehensive community-based system for improving the management of CSHCN. It has been used for successful chronic condition management in an urban school district and has been replicated in other communities.

Limitations of this study include the location of the volunteer sample, which was limited to one state. Although families represented rural, suburban, and urban areas of the state, the mother’s experience with the care of their CSHCN in school may vary by region. The semi-structured questions may have limited the detail offered by participants. Only mothers participated in the survey, limiting the findings to their experiences. Fathers’ experiences also need to be considered in future studies. The mothers were English-speaking only, mostly white middle class, and fairly sophisticated in their knowledge of systems and resources, which limits the transferability of the findings. Although these participants had many advantages, they still had difficulty navigating the systems and obtaining services for their children. Presumably mothers with fewer resources at their disposal would have even greater difficulties.

Describing and understanding the experiences of mothers of CSHCN is an important first step to understanding the care of CSHCN in schools. The results of this study will provide context for the findings from a large national survey of school nurses that has recently been completed. Results from this study and the national survey of school nurses will be used to inform the development of an educational intervention for school nurses to prepare them to care for and to coordinate the care of CSHCN. Knowledgeable and skilled nursing professionals who are adequately prepared to deliver and coordinate services in the hidden health care system (Lear,

2007) that exists in schools today may become an important part of improving outcomes for CSHCN and their families.

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TABLE 1
Sociodemographic Characteristics of the Sample ($N = 10$)

Characteristics	<i>N</i> (%)
School location	
Rural	2 (20)
Small city/suburban	6 (60)
Large urban	2 (20)
Child age	
Min./max.	5–17
Mean	11.3
SD	4.24
Mother's age	
Min./max.	34–52
Mean	42.9
SD	5.26
Mother's race/ethnicity	
White	8 (80)
Hispanic	1 (10)
Asian	1 (10)
Parenting	
Alone	3 (30)
With partner	7 (70)
Insurance	
Private	3 (30)
Combination	5 (50)
Public	2 (20)
Child diagnosis ^a	
Autism	3 (16)
ADHD	1 (5)
Cerebral palsy	3 (16)
Developmental delay	7 (37)
Down syndrome	1 (5)
Hearing impairment	3 (16)
Visual impairment	1 (5)
Care required at school ^b	
Diapering	2 (15)
Medications	3 (23)
G-tube feedings	4 (31)
OT/PT/Speech	4 (31)

NOTE: ADHD = attention-deficit hyperactivity disorder; max. = maximum; min. = minimum; OT = occupational therapy; PT = physical therapy.

^aSome children had more than one diagnosis.

^bSome children required more than one category of care at school.

TABLE 2

Inter-Coder Reliabilities^a

Theme	Interview 1		Interview 2		Interview 3		Interview 4		Interview 5		ALL		
	Total	Agree	Total	Agree	Total	Agree	Total	Agree	Total	Agree	Total	% Agreement	
Communication and coordination	16	16	11	9	12	9	9	9	9	37	85	76	89%
Educational system	8	7	1	1	10	10	9	8	24	23	52	49	94%
Mother as caregiver and expert	28	28	16	15	18	15	11	7	19	10	92	75	82%
Navigating the system	21	20	23	20	17	15	23	20	23	19	107	94	88%
Strategies and coping	25	24	10	9	9	7	6	4	31	28	81	72	89%

^aNumbers are data items (phrases, sentences, or paragraphs expressing a thought).