ORIGINAL RESEARCH

Parental Needs among Children with Birth Defects: Defining a Parent-to-Parent Support Network

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Abstract The objective of this study was to explore how a parent-to-parent support network could impact parents of a child with a structural birth defect by specifically looking at parents' continued needs, aspects influencing their participation in support networks, and their recommendations. Structural birth defects occur in approximately 3 % of all infants, representing a significant public health issue. For many reasons, parents are uniquely qualified to provide support to each other. Data were collected retrospectively through a qualitative approach of focus groups or one-on-one interviews. Thirty one parents of infants registered in the Utah Birth Defect Network participated in the study. Three themes emerged, "current sources and inconsistencies in parent-to-parent-support," "aspects that influence participation in parent-to-parent network," and "recommendations for a parent-to-parent program." Health care providers need to be aware of the services and inform parents about these options. A statewide parent-to-parent network integrated into all hospitals would be a valuable resource to facilitate sharing of issues related to caring for an infant or child with a birth defect.

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Introduction

One of the most important parts of many people's lives is parenting. The birth of a child is one of the most exciting events to which many feel no life experience compares. Though this is a joyous adventure every child born brings life-long responsibilities and challenges. Challenges are intensified with unique stressors when a child is born with a structural birth defect.

Birth defects occur in approximately 3 % (1 in 33) of live births (Martin et al. 2008). These estimates are based on birth defect surveillance programs that exist at the state and national level. In Utah, the Utah Birth Defect Network (UBDN), a statewide population-based surveillance system of most, but not all, major structural birth defects, has been a part of the Utah Department of Health since 1994. A major birth defect, as defined by the UBDN, is any condition present in the infant at birth that is a result of an abnormality of development. UBDN has legal authority to collect information about children born in Utah with birth defects. The Utah administrative rule R398-5 requires all hospitals and birthing centers located in Utah to report a specific set of information to the UBDN any time a baby is born with a birth defect. After the UBDN receives a report, a UBDN representative collects information from the medical records of the infant and the mother from the reporting facility. The information obtained is then entered into a secure database where it will later be analyzed by an epidemiologist to identify rates, trends, risk factors, and causes.

Major structural birth defects and their implications are important to study, as they are associated with many adverse outcomes including an increased risk of premature death,

chronic illness, or long term disability. In the United States and other developed countries, birth defects are the leading cause of infant mortality and contribute significantly to pediatric hospitalizations (Petrini et al. 2002; Kandel and Merrick 2003; Copeland and Kirby 2007; Martin et al. 2008; Melve and Skjaerven 2008; ACOG 2009; Nelle et al. 2009). Understanding this population and providing parents with services should therefore be a healthcare priority.

In addition to the adverse outcomes, the added stress to parents of children with disabilities has been studied in detail (Young 1977; Breslau et al. 1982; Benson et al. 1991; Diehl et al. 1991; Kandel and Merrick 2003; Emond and Eaton 2004; Vermaes et al. 2005; Brosig et al. 2007a; b). Parents must cope with the difficulty of accepting and adjusting to their child's condition, coordinate appointments, manage the financial demands of medical care, find information about their child's condition, and locate appropriate respite care. To manage the added stress, parents have a combination of support options including family, their communities, health care services, and the Internet. Parents may also choose to seek out other parents in similar situations by utilizing parent-to-parent (p2p) networks. The purpose of a p2p network is to connect families going through similar experiences so that they may help each other (Santelli et al. 2001).

Previous studies have evaluated outcomes (Ireys et al. 2001) and reasons parents participating in p2p find value and how barriers negatively impact these support connections (Ainbinder et al. 1998; Konrad 2007; Singer et al. 1999). These studies focused on parents of children with intellectual disabilities, epilepsy, hearing or vision loss, developmental delays, and those who were dying. Although there are needless to say similarities of stressors associated with having a child who has an children with intellectual disabilities, epilepsy, hearing or vision loss, developmental delays, and those who were dying, it is likely that there are also many differences when compared to those with structural abnormalities. This may be due to the perceived significance of intelligence versus physical ability, as well as the fact that many physical abnormalities can be surgically repaired.

Kerr and McIntosh (2000) studied parents of children with congenital upper limb deficiencies and found that the value of a p2p comes from realizing you're not alone, having understanding, having a glimpse into the future, and by helping others. Except the information gained from parents of children with limb abnormalities, little is known about the specific needs and support seeking behaviors of parents of children with a variety of structural birth defects beyond limb abnormalities. The aim of this study was to determine the preferences of parents of children with a variety of birth defects for how and when they would participate in a p2p network and assess factors that may influence participation in a p2p

program. Therefore, this study aims to expand on past publications that add to this topic.

Methods

Participants

The Utah Birth Defect Network (UBDN) served as the data source for case selection (Feldkamp et al. 2005). Utah Birth Defect Network (UBDN), a statewide population-based surveillance system of major structural birth defects. Any time a baby is born with a birth defect the UBDN receives a report and enters this information into a secure and confidential database. This study used this resource to locate a patient population. The study was approved by the Institutional Review Boards of the University of Utah and the Utah Department of Health.

Parents of children born between July 1, 2004 and August 1, 2007 with either isolated or multiple birth defects were eligible for participation. Birth defects included limb reduction defects, anomalies of the skull and face bones, cleft lip and palate, congenital heart defects, gastrointestinal defects, diaphragmatic hernia, and disorders of the kidneys. We only included those who had biological children, not adopted, as we felt those who adopted would have different perspectives and experiences. We did not include infants with known etiologies (i.e., chromosomal, genetic, or teratogen), or those that died. This study only considered parents' with a child between the ages of one to four years. Exclusion of the younger aged children was due to our intention to respect the time needed for new parents to adjust to new diagnoses. Exclusion of older children was due to our expectation that parents' experiences would be different depending on the age of the child (Macias et al. 2003). Additionally, we excluded children with a known etiology as it is likely they have different needs and support available (Rosenthal et al. 2001).

Due to limitations of the research staff capabilities, participants were selected based on their ability to speak English. We included only those who are fluent in English. This decision excluded individuals for whom English was not their language of fluency, who have minimal communication abilities, and who are unable to communicate without an interpreter, thus limiting the diversity of the population under study. However, since this was an exploratory study our decision aided us in maintaining study integrity by insuring that participants fully understood the purpose of the research and were fully capable of verbally sharing their experiences in English.

We mailed letters to 778 mothers inviting parents to participate in this study. A total of 197 (25 %) people responded: 93 (12 %) were interested and 104 (13 %) were

not. Once mothers responded by mail with their interest in participating, they were called to further assess their interest. At that time we verbally invited the fathers to participate as well. Once the focus group and interview details were finalized the parents who continued to express desire to participate were mailed information regarding the time and location as well as a copy of the consent form to review. Of those who were not interested respondents often cited they lived too far away, did not have time, did not feel their child had a birth defect, or considered the defect to be mild. There were 114 (15 %) participant invitations returned as undeliverable. The remaining 467 (60 %) were unresponsive.

Study Design

Parents were asked to share a retrospective perspective of their experiences by participating in one of four focus groups with four to eight parents in each group and lasting between 2 h and 2.5 h. All focus groups, except for focus group 2 (FG2) were moderated by one author (AM) and a co-facilitator. FG2 was moderated by a Genetic Counselor with the University of Utah Graduate Program in Genetic Counseling. Parents unable to attend a focus group were invited for a one-on-one telephone interview lasting between 15 min and 60 min. Among those willing to participate in the interview, all seven interviews were conducted by one author (AM). Participants were asked the same questions regardless of method. Questions were designed to progress from a general discussion of services to specific questions about p2p interactions (Tables 1). To insure consistency a script was developed and utilized for each focus group and interview session.

Qualitative methodology was used in this study because the area of investigation is complex and it allows for the collection of data that do not presuppose questions or

Table 1 Focus group and interview questions

1. Does the term birth defect work for you, if not what would you prefer?
2. What resources were and are available to you?
3. Describe what worked and is working about those services?
4. Describe what did not work and is not working about those services?
5. How could your needs be better met?
6. Would a parent-to-parent be useful to you? (yes or no)
7. What factors influence your participation in a parent-to-parent support network?
 o Why would you participate?
 o Why would you not participate?
8. If a parent-to-parent was started what are your recommendations for participation?
 o Timing and method to approach parent
 o Type of interaction and level of commitment

answers from the population under study. Focus groups allow individuals to build on one another's responses, provide opportunities to collect data in a short period of time, and make it possible to obtain multiple view points (Morgan 1998). The interviews had the advantage of allowing us to reach a geographically wider population.

Data Analysis and Interpretation

The focus group sessions were audiotaped with permission of the participants. Transcriptions of the audiotapes were completed by a professional transcriptionist. One author (AM) reviewed the transcripts while listening to the tapes to ensure their accuracy. To gain an in-depth understanding and to develop a code book, all transcripts were thoroughly read before coding began. All parents were treated as separate participants when coding. Therefore, of the 31 participants, 8 couples or 16 individual, had shared experiences but were coded independently based on their individual responses. The responses were coded and analyzed using the combined methods of content analysis (Mayan 2001) and memo-ing (Miles and Huberman 1994). The codebook was refined when additional interviews or focus groups were analyzed to solidify categories. Categories were discussed with two of the research committee members and later reorganized and integrated into themes with subthemes.

Results

Participants

The study sample consisted of 31 parents (8 fathers, 23 mothers). Twenty-four (7 fathers, 17 mothers) parents participated in focus groups and 7 (1 father, 6 mothers) in individual interviews. The sample represented a total of 23 children (Table 2). Children ranged in age from 14.2 months to 47.3 months with an average age of 27.8 months. Twelve (52 %) of the children had an isolated birth defect and the other 11 (48 %) had multiple congenital anomalies. All demographic data was gathered utilizing the database from the Utah Birth Defects Network. Some parents reported having additional children with birth defects, genetic conditions, or no special health care needs. The parent's number of other children and their health status (e.g., additional child with genetic condition) was not quantified.

Organization of Themes

Three broad themes and several subthemes were identified. All parents contributed similar ideas and expressions. The themes include "current sources and inconsistencies in parent-to-parent-support," "aspects that influence participation in

Table 2 Characteristics of study sample's children

Age of child in months	Total N=23 (%)	FG1 N=4 (%)	FG2 N=4 (%)	FG3 N=6 (%)	FG4 N=3 (%)	Int N=6 (%)
12.0–24.0	11 (47.8)	2 (50.0)	3 (75.0)	2 (33.3)	2 (66.7)	
24.1–36.0	7 (30.4)	1 (25.0)	1 (25.0)	1 (16.7)	1 (33.3)	
36.1–48.0	5 (21.8)	1 (25.0)		3 (50.0)		
Isolated or multiple birth defects						
Isolated						
Cleft lip with or without cleft palate	5 (21.7)			3 (50)	1 (33.3)	1 (16.7)
Limb reduction defects	1 (4.34)				1 (33.3)	
Craniosynostosis	4 (17.4)			2 (33.3)	1 (33.3)	1 (16.7)
Congenital heart defects	2 (4.3)		1 (25.0)			1 (16.7)
Diaphragmatic hernia	1 (4.3)		1 (25.0)			
Multiple (# of major birth defects)						
2–3	5 (21.7)	2 (50.0)	1 (25.0)			2 (33.3)
4–5	2 (8.7)	1 (25.0)	1 (25.0)			
6+	3 (13.0)	1 (25.0)		1 (16.7)		1 (16.7)

N = number of participants. FG(1–4) = focus group, Int (1–7) = interview

parent-to-parent network," and "recommendations for a parent-to-parent program." Please note that the tables provided regarding participant responses are not in any particular order of relevance.

Current Sources and Inconsistencies in Parent-to-Parent Support

Parents identified sources of p2p support including their families, communities, the Internet, and through health care providers. However, many also reported inconsistencies or a lack of p2p support.

Family

One resource was parents' families, which provided help in a variety of ways including p2p connections:

(Interview 1_ female; Int1 _F) "I think probably the biggest resource and the biggest help was my mother-in-law, since she had a child with that condition."

(Int6_ F) "He (husband) had two brothers that were born with a cleft lip … It's lovely to have these two uncles that my children have no idea even had this."

Although participants who received p2p through their family often reported being satisfied, many others did not receive or experience this type of support. Additionally some shared that even when they had someone in their family similarly affected it did not provide them with the support that they needed. One father explained, "My sister's husband has a niece…that has a child with a heart defect. So we talked to them before and we got to see pictures of their baby…And

that was awesome but then after that I never felt like I could call them or anything" (focus group 2_ male; FG2_ M).

Community

Parents shared how p2p interactions were achieved through their communities. Many parents explained having supportive neighbors, "We did know another family who was down the street from my in-laws whose son had the condition" (Int1_F). Some found support through friends, as in one woman's experience, "I have a friend who her son, 4 years older than my son, she's gone through all of it" (FG3_ F). Others found connections through strangers, "I met a lady in the mall 1 day when my little ones were in the NICU and she had a son who had the same thing" (Int3_ F). In addition to meeting other parents, parents often met individuals with the same birth defect as their child, "The biggest thing, it was adults, random adults going, "Oh and I had that, and look at how I am now. Your child is going to be perfectly normal." (FG1_F).

The community was a helpful resource for many; however, there were inconsistencies. Many parents were unable to find p2p connections. This was especially true for parents who had children with multiple congenital anomalies or individuals living in areas with lower population densities. One woman stated, "There aren't any other parents. I mean, there's nobody to talk to about it. There are not many other people in the same situation" (FG3_ F).

Internet

The Internet provided an additional resource. This type of p2p support differed from that found in the community or

Table 3 Reasons to participate in parent-to-parent network

Similar Experiences	(FG4_M) To have someone who's actually dealing with the exact same thing is very helpful…to see someone who has done that or is doing that with your specific need I think helps a lot.
	(FG4_F) Me talking to somebody that needs open heart surgery isn't really relating to anything that I have experienced. If you kept them in groupings of similar conditions, I think that would be helpful.
	(FG2_F) He (child of other parent) has cerebral palsy and my kid doesn't…nothing close to it… But she has horrible feeding issues …and constipation…we had the exact same circumstances.
Emotional	(FG3_F) Just sitting here talking with these two that have had kids with clefts…we've never met in real life…it's like hey, there is someone else. There's a real person out here that I can see that has had a child with a cleft and that's emotionally helpful.
	(FG2_F) This is embarrassing to say, "I don't really want to love my child. I think he's going to die"…I think it would be nice to say to someone…maybe a female over the phone …"what do you do?" … "How do you cope?" … Sometimes you're embarrassed like should I be having those feelings…They can …say, "you're not a bad person"…"You're not a bad parent." "It's natural."
	(FG1_F) But then also because my husband is not there, I feel like I'm a single mom… I mean it would be nice to be able to talk to people about that kind of stuff.
Information	(FG2_F) For two years she had bloody open sores…I wish I would have had a group to say, "Have you ever had this problem?" "What do you do?"
	(Int4_F) Maybe they know something that I don't know or I know something that they don't know, that we can share it with each other.
	Int6_F) I wanted to have a name of a doctor…what's it gonna be like? How long does this take?…Not just oh, it's gonna be okay… Some real hands-on experience, and how many hours, and a doctor's name, and a phone number.
A look into the future	(Int1_F)Well, just to see that he had grown up a little bit. It had been about two years since his surgery and you couldn't really see his scars, and he was just running around like a normal little kid. So it was just nice to see that he can have the surgery and be fine.
Financial	(FG2_M) We've had times where we've struggled and we've had times where we didn't… we had extra money and there was a little girl that needed to get…a heart/lung transplant… so the parents just rallied it up and they all, people are willing to help.
Child care	(FG1_F) But it would be nice to know in an emergency, that well I have this support group of about ten people I can call that understand, "Oh I need to go to the hospital to be with my child."
	(FG1_F) I feel like I'm spending all my time trying to keep the bouncy balls, the nurses gave my son to occupy him, out of the drain of the sink…I'm so focused on my kids, and trying to figure out what the doctor is saying…If I had somebody else it would make it easier.

Table 3 (continued)

Advocate	(FG1_F) It would be nice to have somebody that's on your side. So that when the doctors aren't listening to, and acknowledging your questions, or your concerns, that you have someone to back you up.
Availability	(FG4_M) You're not seeing your doctor every day… we've called up the doctor …You get the nurse or even after hours, you get an answering machine that says leave a message or call this number or go in the emergency room. If you could call someone else and say this is what's happening. This is what I'm going through…Did you go through that same thing? Just to let you know this is normal.
	(FG1_F)You know it would be nice to have something local, where you could like kind of get together, and talk about it.
For the kids	(FG4_F) So that as my child grows up, he has other people to relate to… then he can see what other kids look like…I think it would be nice for him to have friends that are dealing with the same things that he's dealing with.
	(FG3_F) The siblings as well, like my daughter, it's hard for her to imagine that there's other kids just like my son. So I think if she saw another little person running around, it would make more sense.
For spouse	(FG1_F) It would also be nice to have dads that work there. Because I know, my husband is way more comfortable talking to men about stuff. I think it would be more help for him to talk to other men about how it is to be a dad.
	(FG1_M) I want a parent-to-parent…not for me…to help support her (wife).
Helping others	(FG4_M) I may not have done much to help him, but it helped me. I think it was just a way that I felt like I can pay back someone for everything that was done for us.
	(FG4_F) I know how much it would help another mom to be able to have that example that your baby is going to be okay…It's going to be a struggle, but it's going to be okay. Just knowing the effect it had on me would want me to be able to have that affect on somebody else.
Social Interaction	(FG3_F) Sometimes that's the only time you ever get out when you're talking about your kids… so it would be a social aspect. I would get to go with people my own age and talk about grown-up things.

FG(1–4) = Focus group, Int(1–7) = interview, *M* male, *F* female

through the family in two ways. The first was that the interactions were purposefully sought out by the parents instead of random occurrences. One mother, looking for other parents explained how easy it is to find people online, "I mean it sounds crazy, but on the Internet, you find lots of people. I'm constantly finding other local families, and that made a difference for us" (FG1_F).

The second difference is that the Internet allowed people with rarer conditions to connect with other parents. One woman who had a child with a less common birth defect explained, "The thing I found most helpful is the internet to

find support groups and other people that have a similar situation. It's not a very common birth defect, so it's hard to find anybody that relates" (FG4_ F).

7Parent connections on the Internet also had some inconsistencies. A parent explained, "I went on the Internet like crazy, but you don't get a lot of information if you don't know what you're looking for" (FG3_F). Parents often reported difficulties when they visited an online support group's website. One mother stated, "I didn't like the way it was set up just because it's all one big long (post), so you can't go… I'm looking for … the lip repair… you have to read through everything to find that…through the 3,000 posts" (FG3_ F). Furthermore, not everyone had Internet access. One participant said, "I don't even have a computer" (FG2_ F). Those who found support often expressed their frustration with lack of local support. As one woman explained, "I found a bunch of Internet groups with national stuff, and I felt that I don't want to sign up with all these people across country" (FG1_ F).

Health Care Services

Some parents spoke of their experience and appreciation with health care providers, genetic counselors, or services that coordinated p2p including physicians, social workers, other health care providers, or through a shared room while their child was in the hospital:

> (Int1_ F) "We had a room that we shared with another family whose child had the same surgery… I think it was, like, the camaraderie of I know what you're going through and you know what I'm going through."

Again there were inconsistencies reported. One parent, after hearing other parents share about receiving assistance locating other families exclaimed, "I never heard about that. No one, no nurse, no one ever told us about that. And I would have loved to attend" (FG1_ F).

Another common problem explained was parents being lost in follow up. One woman shared, "One of the questionnaires they gave us in the NICU, are you interested in talking to another family that has a similar condition? And we put yes, and no one ever followed up with that…I called and said, "Is there any parent support groups for heart defects?"…someone finally said, "No, not really". And I found out later there was one" (FG1_F).

Aspects that Influence Participation in a Parent-to-Parent Program

Parents were asked if they felt a p2p network would have been useful for them. The majority of parents, that is 21 of 23 (91 %) of the mothers, expressed that it would have been valuable. However, only 4 of the 8 (50 %) fathers expressed interest. Therefore, one could presume that gender plays a role in desire for participation and support needs.

Participants who were interested in a p2p network spoke specifically how other parents provide a unique form of support and their reasons for wanting a p2p network (Table 3). These reasons included having someone to share similar experiences with and interact with socially and through advocacy. Other parents can provide emotional and informational support and they are also available when health care providers are not. Many felt that this would provide them a look into the future when they met a child with the same birth defect as their own. Others still felt there may be benefits with regards to financial assistance, childcare, and way to help others and their spouse. Not only are they a support for the parents, but also for the children.

All parents identified barriers to participation in p2p networks (Table 4), including distance, finding a babysitter, or when required to provide time and money. Many people expressed their concerns working with people who have a child with a more or less severe version of the same condition. Gender differences and personality conflicts would also deter parents from participating. Parents reported having a fear of being judged and they explained situations in which parents may not act as supports by trying to fix their problems rather than listening and by focusing on their own needs.

Of the six parents who reported a p2p would not have been useful (Table 3) their reasons included that their child's condition was mild, some had enough support through existing support systems, and others would rather talk to professionals or experts. However, those who stated a p2p would not have been helpful often recognized the need for support for their spouse or if their circumstances would have been different.

> (Int7_ F) "I could see…if he had a more severe condition, if he had to have surgery or had something that impacted his everyday life, I would definitely be interested in having communication with other people of a similar condition."

Recommendations for a Parent-to-Parent Program

Participants identified some preferences and recommendations for how a p2p network could operate (Table 5). Parents had many experiences and thus varied considerably in their preferences for how they preferred to receive support. These preferences included their recommendations for the timing of when to first approach a parent about the opportunity, how they would like to be approached, how often to approach a parent, the type of interaction (phone, internet forums, face-to-face, etc.) with other parents, and their own commitment level to a network.

Table 4 Barriers to participate in a parent-to-parent network

Reasons not to participate	Not serious	(Int1_F) He healed really quickly…we went in for some check-ups, just some follow-ups, and everything looked fine…so we didn't really feel like we needed any extra support afterwards, just because everything was fine.
	Enough support	(Int1_F) I just felt like we had so much support that it wasn't something that I felt like would have been helpful.
		(FG1_M) I've got my own support group; I've got my own close friends…And I've got my wife, I've got my family, and if I need support I turn to them. And I don't typically go away with a bunch of guys that I only see once a month.
	Prefer experts	(FG1_M) It was more about talking to the experts… I'm more comfortable with the nurse, because she knows all the facts, she can get all the detail stuff, gives me all the leads on stuff.
	Lessening need	(FG3_M) Sometimes you outgrow the condition. Outgrow the need for it and kind of get tired of repeating their experiences.
Barriers to participation	Distance	(Int3_F) I live in the middle of nowhere… I feel a little far away from where it's all happening…it just doesn't seem like it's something that I'm able to do from where I am… I think the only reason I wouldn't is the distance.
	Limited resources	(FG1_F)You are afraid they are going to ask for your time and your money…We are so busy as it is…I think when you ask for time or money, or you're afraid that they will require that of you, then that's a concern.
	Babysitter	(FG2_F) It's hard to make time to get a babysitter every, you know, once a month or whatever…if they decide to do a lunch.
	Gender differences	(FG1_M) I don't personally see a dad networking, because it's going to turn into sports, or something.
		(FG2_M) I would rather have a woman…I don't like that maleness soothe kind of thing… It depends on if they were just talking to you or talking to (a couple)…. couple to couple that's fine. If it's a woman in the couple it's fine. If it's a man in the couple it's fine but if it's man to man it's weird"
	More/less severe	(FG2_F) We met another lady that had a daughter with…And hers died… You can become paranoid….I just wanted to hang up the phone because he was…having surgery. And I'm like, don't talk about him dying…it was just the same disease too but she had actually had a transplant and it died… I didn't want to hear her story. I didn't want to talk to her.
		(FG3_F) Hearing people complain about their child's conditions that wasn't even nearly as bad as yours and they act like it's the end of the world…I know it was hard for them… but for me to hear that and here my child's going through way, way worse things, I just cut it off.
	Fear of being judged	(FG1_F) I just feel like somebody might say something…Somebody making me feel like I'm stupid…Some people are very over bearing, and just can make you feel … inferior.
		(FG3_F) I get really self-conscious like they're gonna look at me like I'm a terrible parent… I don't want them to look at me and say, "Why the crap did you do that?"
	Does not support	(FG3_F) Some people like to tell me, "Oh…it'll get better." It's like no. They're like trying to reassure you and you're like that doesn't even help me. You just wanna be heard.
		(FG1_F) Sometimes people that I talk to have had children with defects…people are just like, "Oh let me tell you my story." Who cares about your story?…Everybody thinks it's the same, but it's not the same…It's like you go to this parent group and they're all going to tell me, well I have this and I know exactly what you're doing.
	Personality conflicts	(FG1_F) I think it's a little harder for parents, that aren't really out going, and loud. Because I know, me and my husband are kind of on the shy side. So we aren't the kind of people, to go out and search for that kind of stuff.
		(Int6_F) (other parent) is a really good friend of mine, but her personality…is a little more extreme…it could be bad just because of personalities..

FG(1–4) = Focus group, Int(1–7) = interview, *M* male, *F* female

Parents recognized the ideal timing to tell a parent about p2p depends on individual circumstances; however, many gave specific suggestions including as soon as possible, need time to process, at a follow up visit, and not in the prenatal period. Participants suggested using letters, pamphlets, Internet resources, or the UBDN to educate parents about p2p. They reported the importance of having multiple sources offering p2p at multiple times throughout their

Table 5 Recommendations for a parent-to-parent network

When to approach	Depends on situation	(FG2_F) It will be different for everybody.
		(FG3_F) I think it depends on what the diagnosis is.
	As soon as possible	(FG4_M) Don't wait a long time…You might need this right now to help deal with what you're going through.
		(FG1_F) I wanted information right then.
	Need time to process	(FG2_F) It just wasn't the right time for me…but later on when I was at home then you didn't feel as secure.
	At follow up visit	(Int1_F) We were referred a couple of times. First, we went for a CAT scan, and then, we got referred to (location)…it seems like at that point it might be interesting to get information.
	Not Prenatal	(FG4_F) Prenatally…would be hard because you're talking about something you don't know anything about.
How to approach	Letter	(FG1_F) I want a letter, or an e-mail.
	Pamphlet	(FG2_F) It can be as simple as just a card you get at your pediatrician that you sign up for your next appointment or…pamphlet.
	Website	(FG4_F) I would love it if there was a website.
	Through UBDN	(FG4_F) If they're mandated to register you on the (UBDN), they could ask you at that point …Then it's just part of that network…even if they just had a little questionnaire to fill out.
How often to approach	Multiple times	(Int6_F) I think… you have to ask women a couple times.
	Multiple sources	(FG2_F) I think the problems we run into though is it's got to be in multiple places… if you have it in many different places, you're eventually going to get it at some point and maybe it's at the point you need it.
	Good to reoffer if previously rejected	(FG4_F) Sometimes, we feel like I've got it under control …other times, it's like crap, I wish I could talk to somebody. It really does fluctuate at different times. I don't see a problem with offering it all the time.
	Would not be offended	(Int1_F) I wouldn't have been offended if somebody had asked me once and I said no and they asked me again at a later date. That wouldn't bother me.
Type of interaction	Internet	(Int4_F) Over the Internet…I can do that at the nighttime when she is asleep…if they were a long distance away, that would be the easiest for me.
	Phone	(FG2_M) A lot of times you can just say stuff that you wouldn't normally say…you say so much more on the phone.
	Face-to-face	(Int1_F) Face-to-face…then you can get the emotion of the other parent and really understand what it was and what they're going through.
	Group	(FG1_F) If I have question or if someone else has a question that I might have insight on, then I think the group is better.
	One-on-one	(Int6_F) Some of those group things I get really uncomfortable with…It feels so artificial… I think a conversation…rather than a formal group discussion.
Commitment Level	Leader	(FG1_F) I personally would fully participate…I could see myself being the head of group.
	Participant	(FG1_F) I'd rather just be a participant…I don't want all the responsibility.
		(FG1_M) I'm just happy to support her (wife) being a member.
	Only in community	(Int1_F) If it was somebody that I knew or somebody called me …then I would definitely say, "Yes." But I'm not sure I would necessarily put myself on a list.

FG(1–4) = Focus group, Int(1–7) = interview, M = male, F = female

child's care. Many felt it was beneficial to be reminded of these services and all parents stated they would not have been offended if p2p was reoffered at a later date if they had previously rejected. Parents had specific needs for how they interact with other parents including in a group, one-on-one, over the Internet, face-to-face, or over the phone. Some parents could see themselves as leaders, as participants, or as a support in their community.
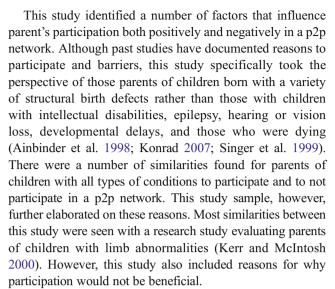
Discussion

It is clear from the parents' reflections that the birth of a child with a structural birth defect results in emotional, informational and practical support needs. Parents satisfy these needs in a number of ways. Many parents receive support through their community or as an existing part of their family. However, not everyone has this type of support

available. These types of health care disparities are especially true for those who live in rural locations or with children who has less common types of birth defects (Saywell et al. 1993; Telfair et al. 2003; Beene-Harris et al. 2007; Case et al. 2008). Even of the study participants who did have connections through their family or community may not have been satisfied with the level of support they received. Other parents made these connections through health care services; yet, there appears to be a number of inconsistencies about who is receiving this information and if healthcare providers are following up with arranging these connections. Although parents' perceptions may not reflect what actually occurred, the findings of this study concur with previous research that suggests that making these connections could be better coordinated (Sloper and Turner 1993; Kerr and McIntosh 2000). Parents often reported that because these p2p connections were not made they took it upon themselves to find other parents by locating them through the Internet. This is consistent with the literature that states that over 61 % of American adults use the Internet to find health information (Fox and Jones 2009). Despite the amount of health information available online, there are several barriers that limit the Internet from being adopted a source of health information and support including operator skill level, incomplete or incorrect information, and the ability of the patient to synthesize relevant information and use it practically (Benigeri and Pluye 2003; Warschauer 2003; Van Deursen, and Van Dijk 2011). Although this has proven successful for many, our study population often reported that they too found the Internet to be difficult because of limited access, lack of local support options, or because of the confusion of sorting through information that may be unorganized, too technical, or upsetting.

The majority of participants reported they would find value if a p2p network existed. However, some parents reported that they did not personally need the support. Of note, there was a gender difference in the desire for support services. The majority of mothers, that is 21 of 23(91 %) expressed interest, where as only 4 of 8 (50 %) of the men expressed interest in participating. There are a number of studies that suggest that men are less likely than women to seek help from health professionals for problems as diverse as depression, substance abuse, physical disabilities and stressful life events, such as having a child born with a birth defect (Thom 1986; Lewis and O'Brien 1987; Padesky and Hammen 1981; Corney 1990; Husaini et al. 1994; O'Dowd and Jewell 1998). Therefore, one may presume that men are less likely to participate in this kind of support network. However, the men who stated they were not interested commented on how p2p would have been valuable if their circumstances were different and they recognized the need for their spouse.

This study identified a number of factors that influence parent's participation both positively and negatively in a p2p network. Although past studies have documented reasons to participate and barriers, this study specifically took the perspective of those parents of children born with a variety of structural birth defects rather than those with children with intellectual disabilities, epilepsy, hearing or vision loss, developmental delays, and those who were dying (Ainbinder et al. 1998; Konrad 2007; Singer et al. 1999). There were a number of similarities found for parents of children with all types of conditions to participate and to not participate in a p2p network. This study sample, however, further elaborated on these reasons. Most similarities between this study were seen with a research study evaluating parents of children with limb abnormalities (Kerr and McIntosh 2000). However, this study also included reasons for why participation would not be beneficial.

Regardless of whether parents were personally interested in a p2p network, they offered a variety of recommendations for a p2p network. There were multiple suggestions reflecting the requirement for a flexible program with many options in order to satisfy the unique needs of parents in a variety of circumstances.

We concluded from this study that a p2p network serving as a statewide service through a birth defect surveillance program and integrated into all hospitals is desired and needed for the appropriate management and care of parents with children that have structural birth defects. These types of connections are important to parents and parents gain a great deal of value from them. Consequently, there is a need for health care providers to be aware of p2p services and to actively inform parents about the options available to them.

Study Limitations

The limitations include possible participation bias regarding the views of the parents wanting a p2p. It is not possible to determine the need and level of support already existing for the parents who participated compared to those who did not respond. Another limitation is that parents of children with a wide range of birth defects, either isolated or multiple, were included. It was decided to include many conditions in order to receive a variety of perspectives and because any single birth defect may be too rare to obtain desired numbers of participants. Parents often reported other children in their families with birth defects and genetic conditions. Although we asked participants to focus on their experience with the child of interest, it is possible that parents reported their combined experiences of parenting. Additionally, although we excluded those with a known etiology, we do not know that later in life if they will receive a specific diagnosis.

Other limitations existed in the collection and analysis. Two methods, interviews and focus groups, were used.

Participants interviewed individually may have contributed more sensitive information as discussions were conducted privately, one-on-one, and over the phone rather than in a group and in person. One of the four focus groups was led by another facilitator. The data from this group were analyzed separately and no significant differences in results were found. Other limitations are inherent in the focus group process including non-independent responses and inhibition to share honestly due to a group atmosphere (Morgan 1998). To alleviate these problems participants were encouraged to write down responses and turn them in to the facilitator at the end of the meeting. The population was small and all members were from Utah, thus the results may not be generalizable.

Other possible limitations include the lack of diversity in participants, fewer males then females, fewer participants living in rural locations, the possibility that some interview questions were leading, the data was collected retrospectively possibly causing some recall bias, and we treated couples as if they were separate entities which may have exaggerated the degree of similarity in responses.

Future Research Possibilities

Using a qualitative approach we attempted to evaluate the reasons parents would or would not participate in a p2p program and to gather their recommendations for how a network would operate. Participants had a variety of experiences that contributed to their preferences and recommendations for implementation and management of a p2p program. Some differences included severity of conditions, degree of personal experience or knowledge about the birth defect, treatment options, and when they learned of the diagnosis. A quantitative study would make it possible to clarify reasons and preferences while comparing these differences as well as demographic information, existing support networks, geographical locations (e.g., rural and urban), and type of structural birth defect (e.g., internal or external and multiple or isolated). A qualitative study has the advantage of larger sample sizes and the relative simplicity for data collection may enable parents who would not otherwise participate to share their thought and experiences.

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