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Deaf Mothers and Breastfeeding: Do Unique Features of Deaf Culture and Language Support Breastfeeding Success?

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Abstract

Background—Deaf mothers who use American Sign Language (ASL) consider themselves a linguistic minority group, with specific cultural practices. Rarely has this group been engaged in infant-feeding research.

Objectives—To understand how ASL-using Deaf mothers learn about infant feeding and to identify their breastfeeding challenges.

Methods—Using a community-based participatory research (CBPR) approach we conducted four focus groups with Deaf mothers who had at least one child 0–5 years. A script was developed using a social ecological model (SEM) to capture multiple levels of influence. All groups were conducted in ASL, filmed, and transcribed into English. Deaf and hearing researchers analyzed data by coding themes within each SEM level.

Results—Fifteen mothers participated. All had initiated breastfeeding with their most recent child. Breastfeeding duration for eight of the mothers was three weeks to 12 months. Seven of the mothers were still breastfeeding, the longest for 19 months. Those mothers who breastfed longer described a supportive social environment and the ability to surmount challenges. Participants described characteristics of Deaf culture such as direct communication, sharing information, use of technologies, language access through interpreters and ASL-using providers, and strong self-advocacy skills. Finally, mothers used the sign ‘struggle’ to describe their breastfeeding experience. The sign implies a sustained effort over time which leads to success.

Conclusions—In a setting with a large population of Deaf women and ASL-using providers, we identified several aspects of Deaf culture and language which support BF mothers across institutional, community, and interpersonal levels of the SEM.

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CONFLICT OF INTEREST

The authors have no conflicts to disclose.

BACKGROUND

Deaf women who use American Sign Language (ASL) as their preferred means of communication often self-identify as part of a unique cultural community, bound together by a common language and specific values, practices and norms. Deaf people who identify themselves as part of a cultural group use a capital 'D' to spell Deaf. The convention of using a capital 'D' to spell Deaf signifies that the person is attached to a community, which uses ASL and Deaf cultural norms as part of their everyday lives. A lowercase 'd' in deaf indexes audiological rather than cultural status—a convention we follow in this paper.¹

Deaf Communities/Deaf Culture

In the cultural model of deafness, hearing loss is not seen as a defect in need of repair, but rather as the basis of a language community.¹ Use of ASL is more important for membership in the Deaf community than is documented hearing loss.¹ ASL is not based on English. It is a unique language with its own syntax and grammar, conveyed using three dimensional space, hand-shapes, motion, and facial expressions.^{2,3} The exact number of people who use ASL and consider themselves Deaf is unknown, but researchers have estimated between 250,000 to 1 million ASL users in the US.⁴

Health behavior data from Deaf people are limited. Most national health surveys are conducted via telephone, automatically excluding deaf participants. On other surveys, such as the National Survey of Family Growth, deafness is part of the exclusion criteria.⁵ A recent health behavior survey delivered in ASL to a large sample of deaf adults in Rochester identified higher rates of obesity among them when compared to a local hearing sample, suggesting Deaf adults might have restricted access to nutritional information.⁶

Access to health information for Deaf individuals is impeded in many ways. Nine out of every ten children born deaf have hearing parents.⁷ Many families, intent on 'fixing deafness', never learn ASL, making communicating with their deaf children sub-optimal. Family health histories and infant care practices may not be explicitly handed down from hearing family members to deaf children. Radio advertisements promoting breastfeeding, discussions among hearing mothers, and other forms of over-heard information cannot be accessed by Deaf women. Health information available in written English is only accessible to Deaf mothers bi-lingual in both ASL and English. The best available data show that deaf high school graduates read at the 4th grade level.⁸ Deaf people's limited English literacy has important implications for public health as most health information available in written forms such as brochures, flyers, signs, newspapers, magazines, captioned TV, and Internet are typically written for people who are able to read English at the seventh grade level or higher.⁸ For Deaf mothers fluent in written English, communicating through written notes with their provider may be a challenging way to have questions answered during a busy prenatal visit. Many visits are not conducted with ASL interpretation, despite the protections offered by the Americans with Disabilities Act (ADA). The reasons for this are varied. There is no formal certification and little specialized training in medical interpreting, so the medical vocabulary skills of interpreters varies. Additionally, the preference for direct communication, scarcity of interpreters, privacy concerns, and lack of ADA compliance by healthcare providers may increase the dependence on written provider/patient interaction.⁹

How Deaf women access information about infant-feeding, how they negotiate barriers to optimal breastfeeding practices, and ultimately, how they feed their infants, are unknown. Given the unique aspects of Deaf culture and the limited availability of ASL-using providers and interpreters, it is important to understand how Deaf women learn about and experience breastfeeding. As a first step towards this goal, the objectives of this study are to understand how Deaf women in Rochester, New York get information about infant-feeding and to identify barriers and facilitators to breastfeeding.

METHODS

Community Engaged Research

This work unites two CBPR projects at the University of Rochester School of Medicine and Dentistry: the Prevention Research Center at the National Center for Deaf Health Research (NCDHR) funded through a grant from the Centers of Disease Control and Prevention (CDC) and a National Institutes of Health (NIH) funded study to generate institutional and community support for breastfeeding in low income communities. NCDHR was established to conduct research on health disparities between hearing and deaf people. NCDHR subscribes to a cultural model of Deafness. Its research is not concerned with the etiology of nor a 'cure' for deafness, but how to close the gap in health disparities between Deaf and hearing people.

Guidelines for CBPR describe a process of mutual learning between academic researchers and community members. This mutual learning ideally results in jointly identified research problems, methods, and analysis.¹³ Adhering to the principles of community-based participatory research, this study was initiated in direct response to a request from members of the Deaf community in the Rochester area and conducted by Deaf and hearing researchers.

Theoretical Framework

We applied a social ecological model to understand the infant-feeding behaviors within a broad multi-level context that considers higher order structures in shaping the infant-feeding experiences for deaf mothers.¹⁴ This framework accomplishes multiple objectives: 1) it draws attention away from the individual mothers' behaviors to consider the wider social context that influences feeding decisions; 2) the model describes four other interacting layers of influence which need to be activated to optimally support individual behaviors; and 3) it avoids the individualistic reductionism which narrows potential interventions to those educating mothers on lactation management.

Recruitment

Participants were recruited through flyers e-mailed to local Deaf organizations, including the Deaf Moms Club of Rochester, and the NCDHR listserv, posted on Facebook, and through an ad in the electronic newsletter *The Deaf Times*. A \$25 gift card incentive was offered. Although recruitment materials were in written English, the venues we used for distribution quickly spread the information from person-to-person in ASL. Interested women were included in the study if they considered themselves culturally Deaf, used ASL, and had a

child 0–5 years. The method of infant-feeding—formula, breast milk, or mixed—was not a criteria for inclusion. The University of Rochester institutional review board approved this study’s protocol.

Research Setting

Rochester reportedly has highest per capita concentration of Deaf individuals in the US.¹⁵ Deaf individuals here tend to be highly educated, hold professional positions, and have multiple opportunities to socialize with other Deaf people through community sponsored events. There are Deaf bowling leagues, Deaf Euchre tournaments, numerous Deaf civic and social organizations, open-captioned movies at area theaters, and Deaf specific education for both the K-12 and post-secondary levels. Additionally, the National Technical Institute for the Deaf at the Rochester Institute of Technology regularly offers accessible theater productions, poetry readings, and national speakers on issues important to Deaf people which are open to the community at large.

The unique social organization of Rochester’s Deaf community is partially rooted in historical circumstances. Deaf people initially were drawn to the city in the late 1800s through employment in the printing press industry. The terrific noise of the printing press represented a occupational hazard for hearing people and deaf printers were in demand.¹⁰ The Rochester School for the Deaf was established in 1876, providing specialized education for Deaf and hard of hearing children.¹¹ In 1968, Lyndon Johnson established the National Technical Institution for the Deaf at the Rochester Institute of Technology¹² providing both education and employment for Deaf people. Many Deaf professionals appreciate the deaf-friendly environment and either relocate to this area or stay after graduation.

Focus Group Protocol for Deaf Communities

Given historical paternalism and exploitation between hearing and deaf people, the research team decided that only ASL-using Deaf members of the team would moderate and assist at focus groups. Based on our prior work with Deaf adults¹⁶ we used two video cameras to capture the discussion. An experienced bilingual Deaf research assistant translated and transcribed the video tapes into English for analysis.

Data Analysis

The Deaf-hearing research team reviewed transcribed interviews looking for recurring events, metaphors, terms, and social actors.¹⁷ These were then organized under higher order themes and sorted across the levels of the social ecological model. Respondent verification involved presenting preliminary findings to a regularly scheduled meeting of Rochester Deaf Moms Club, a community support group, for feedback and revisions.¹⁸

RESULTS

We recruited 15 mothers to participate in focus group discussions. In order to capture information from mothers who both formula fed and breastfed, method of infant-feeding was not part of inclusion criteria. Despite the non-targeted recruitment materials, all 15 participating mothers had initiated breastfeeding. Breastfeeding duration in this small group

ranged from two weeks to 19 months. Some of the mothers were still breastfeeding at the time of their participation (Table 1).

All mothers thought of breastfeeding as healthier for infants than formula feeding. Their information about the importance of breastfeeding came from web sites, books, parenting magazines, and health care providers. Beyond these sources of information our analyses identified cultural features of Deaf community interaction and language that supported breastfeeding success, including: 1) ASL visual depictions of behaviors, including the conceptualization of breastfeeding as 'struggle'; 2) Deaf cultural norms; 3) use of communication technologies for problem solving; 4) language access provided by a well-trained ASL interpreter workforce in Rochester and ASL fluent health providers; and 5) strong self-advocacy skills. These features spanned multiple levels of the social ecological model (Figure 1). Each of the five features is described below.

1. American Sign Language a Visual Language

ASL is a graphic, visual language that describes behaviors in three dimensions using hand motions, body language, and facial expressions. Such detailed explanations of problems in breastfeeding are potentially more amenable to problem solving than are spoken language descriptions. Renditions of ASL into English are interpretations of three-dimensional signs that have multiple, context-dependent meanings. Any English word used during translation from ASL is merely a gloss of the layers of meaning embedded in a single sign. Surprisingly, almost all of the mothers used the sign "struggle" to describe how they learned to breastfeed. Deaf mothers told us:

Breastfeeding was a **struggle**. - Claire, FG#1

It was a **struggle** and I stayed in the hospital for three days to get extra support from the lactation consultant...I **struggled** with breastfeeding ...I had to try different techniques. I worked with a lactation consultant and got a lot of ideas.- Mary Ann, FG#1

At three weeks, I **struggled** too. The nurse kept coming and trying to help me. The baby kept refusing. We tried to calm him down and get him to eat. It was a **struggle**. - Claire, FG#1

When my first son was born, I **struggled**. It was frustrating, which is typical with the firstborn. I had a breastfeeding specialist. I forgot what they're called but it helped and I got the hang of it and things improved. I breastfed him for 14 months. -Margie, FG#2

I was determined to breastfeed. With the first daughter, I **struggled**. I [eventually] was able to breastfeed. -Josie, FG#2

The only thing I **struggled** with was breastfeeding. That's all. -Annie, FG#4

In ASL, the sign rendered into English as "struggle" is presented by the index fingers on opposing hands pointing at one another and moving back-and-forth with an indication of a circular *process* of give and take. The two index fingers represent a dyad, in this context a process occurring between the mother-infant pair. The movement of the sign implies

repetition over time, and persistence. Associated facial expressions indicate determination, rather than frustration. The body language implies focus. The use of this sign suggests a learning process for both mother and infant. Deaf mothers at the respondent verification session endorsed and added to this interpretation, noting that the sign, body language, and facial expressions carry the air of ‘not giving up in anticipation of eventual, hard won success.’ They were perplexed by what terms hearing mothers used to describe breastfeeding challenges. When we told them hearing mothers used terms such as, ‘frustration’ and ‘discouraged’ Deaf mothers responded negatively, indicating this is not what they were conveying with the sign “struggle”.

2. Deaf Cultural Norms

The Deaf community in Rochester is tightly knit. Members give one another social, informational, and emotional support. The group interactions in Focus Group #4 poignantly illustrated this theme. Cynthia, new to the Rochester area, had little financial or social support. She felt isolated and unprepared for some of the challenges of parenting her two children. Her daughter was born hearing. Her son, who was younger, was born deaf and by Cynthia’s description, had behavioral problems. Annie and Vickie, long time members of the Rochester community, were in the same focus group as Cynthia. The women told stories that explained the parenting challenges they faced and how they activated social networks, accessed information, and established key alliances with hearing people to overcome parenting difficulties.

Cynthia: *My son doesn't have much social interaction. I need to take him out more.*

Annie: *You could contact his classmates' parents. Some may be deaf like you. Most of the kids' parents are hearing. There's no difference.*

Cynthia: *He stays at home a lot. He needs to get out and have a good time. Sometimes he picks on his sister too much and they're mean to each other.*

Annie: *I went through that. I wondered who my kid was going to play with. My friends were gone or they didn't have a baby. I had to get through it. I had to be assertive and meet people.*

Repeatedly, Annie and Vickie gave Cynthia information and strategies about parenting without judging her.

Deaf cultural norms emphasize support of the kind Annie and Vickie offered placing a high value on the exchange of information, in part because information in a hearing dominated world is hard to come by for Deaf people. Deaf communication is very direct, to an extent that may seem blunt or intrusive by hearing standards. One of the Deaf mothers in our study learned about the importance of breastfeeding in this manner:

I remember going to a birthday party when I was pregnant. A mother came up to me and told me to be patient about breastfeeding because it’s not easy. She reiterated the importance of this patience...and I took her words seriously. - Lissa, FG #2

In the deaf community very direct communication with an unknown person is not considered intrusive or rude. Rather, communication norms favor information sharing and are considered a valuable part of deaf social life. Giving advice to a stranger is considered part of being a responsible member of the community⁸.

3. Use of Technology

Deaf mothers in our focus groups used technology to both increase their information about breastfeeding (videos, YouTube) and to reach out for support from other mothers (Facebook, e-mail, texting). Mothers told us:

I had an e-mail from my step-sister saying that breastfeeding was the toughest physical challenge she ever faced in her entire life and it was not easy. That gave me motivation when I realized that other mothers struggled too. –Amilia, FG#1

I get information from the Internet. I talk to my doula. She's great for support. I found people like me when I took the Bradley class so I contacted them for information. - Mary Ann, FG#1

Participant: *I asked my mom what to do and I've also posted on Facebook to see other mom's responses and compare notes.*

Moderator: Did you get a lot of feedback?

Participant: Oh, yes. I got like 28 comments. – Colleen, FG#1

4. Language Access

Language access to health providers – physicians, nurses, doulas, and lactation consultants - are supported by a large cadre of certified sign language interpreters who work in the Rochester area.

In addition to the availability of interpreters, several practicing physicians are sign language fluent, including two family medicine doctors and one Obstetrician-Gynecologist. Women in our focus groups indicated that optimal communication was possible when their doctors could communicate with them through sign language.

How did I know about breastfeeding? My doctor told me [in sign language]. He explained breastfeeding and encouraged it while I was pregnant. Fine. My OB/GYN explained breastfeeding to me [in sign language]. Fine. So I kept it in mind. Signed communication helps a lot. – Annie, FG#1

5. Self-Advocacy

The majority of the Deaf mothers in this study were well educated. They were proactive in asking for help from health professionals, even seeking out doulas, who used sign language and directly requesting extra services when they felt stuck:

...I called the doctor and asked him to send someone to my house. He sent a nurse who explained that I had to relax because I was so tense and nervous. If I relaxed, my daughter would latch on because when I'm nervous, she is too...So I relaxed

and sure enough, she latched on and it was successful. I breastfed her exclusively for 10 months. I didn't use formula or anything else. -Claudia, FG#2

Members of the Rochester Deaf Moms Club explained that self-advocacy is a behavior they learned early and used often throughout their lives. Reaching out to professional services when they needed assistance was commonplace in this group of Deaf mothers.

DISCUSSION

Our findings suggest there are specific features of Deaf culture and language that uniquely support breastfeeding among Rochester Deaf mothers. Using the social ecological model to organize focus group data, we identified factors on multiple levels that created the conditions supporting successful breast feeding. These included communication norms that encourage direct exchange of information with other deaf people and a set of self-advocacy skills developed over their life-times. Given that deaf individuals have limited access to auditory information we expected to find a lower fund of information among study participants. A low-fund of information among Deaf adults has been reported regarding other health behaviors: diet and exercise,¹⁶ prenatal care,¹⁹ and obesity prevention.²⁰ Unlike these studies, we did not identify a similar low fund of information. In describing their experiences with breastfeeding, Deaf mothers identified multiple ways they accessed information: fellow Deaf community members, ASL-fluent health care providers, YouTube videos, Facebook sharing, and the use of sign-language interpreters to communicate with non-ASL using health care providers.

The most unexpected finding was the ASL conceptualization of breastfeeding as “struggle”. Social linguists have pointed to the use of metaphors as providing tools for shaping the way a people think about an activity.^{21,22} Ted Supalla, an ASL scholar, wrote of the sign for “struggle”, “One of its meanings is ‘to figure out how to do something independently.’ An analogous concept in English might be phrased: ‘It took me a while to figure it out, but I did’” (personal communication to the authors). The sign “struggle” seems to conceptualize breastfeeding as a process embedded in the developing relationship between mother and child. The cyclical movement of the sign suggests persistence until the intended, successful, outcomes are achieved.

These findings are important to the promotion of breastfeeding in the national population of Deaf women in the US, many of whom, unlike the Deaf women of Rochester, are relatively isolated from other Deaf people and ASL-users.

This study's findings may also benefit programs to increase breastfeeding duration among the general population of hearing mothers. Hearing mothers across ethnic groups generally know “breast is best”. Nevertheless, while the breastfeeding initiation rates in the US have increased over the past 8 years, rates of exclusivity and duration are still relatively low. In 2011, only 14.8 percent of US mothers followed the clinical recommendations of breastfeeding exclusively for the first six months.²³ The reality of breastfeeding for all mothers, Deaf and hearing, is that learning how to breastfeed can be hard. Many social barriers to success exist.²⁴ Re-conceptualizing breastfeeding through ASL ‘struggle’ may

better prepare hearing mothers for the learning process, decrease their frustration, and encourage them to persist in their efforts.

This study has several limitations. We were unable to recruit a diverse ethnic sample of deaf women; no women of color participated in the focus groups. Future research needs to address Deaf mothers of different racial and ethnic backgrounds, educational levels, occupations, LGBT mothers, and Deaf fathers.

Although recruitment materials did not target breastfeeding mothers, none of the mothers in our sample had initiated infant feeding using formula. Finally, all but two of the mothers were highly educated having at least some college. In deaf communities this does not necessarily correlate with income or occupation as even well-educated deaf people are often under-employed and under-paid⁶, but this did reduce the groups' diversity. Finally, there is a high level of support for Deaf women in Rochester, which limits the ability to generalize findings to other Deaf populations in the US.

CONCLUSIONS

Our study done with Deaf Mothers in Rochester, NY, sheds light on how Deaf mothers get information about infant-feeding and how they negotiate barriers to breastfeeding. We were able to identify several components of Deaf language and culture as supportive in breastfeeding. Specifically, the community of Deaf mothers is highly networked through technologies that help them exchange information and problem-solve (videophones, social media sites, and texting). The community values direct communication; has access to ASL-fluent health care providers; and has developed strong self-advocacy skills over their lifetimes. Furthermore, Deaf mothers frequently used the sign for 'struggle' to describe their breastfeeding efforts. We postulate that this provides them with conceptual tools needed to anticipate challenges in establishing breastfeeding and encourages them to be persistent in their efforts.

This research is significant in several additional ways. First, this study has shown that minority communities can overcome barriers and achieve a goal. The community participatory paradigm is crucial in making these discoveries. Deaf women were enthusiastic participants in focus groups, willing to share their knowledge through robust stories of personal experiences. Our use of Deaf researchers to moderate and assist at the groups turned out to be key in uncovering these stories. Secondly, using the CBPR framework has enabled a bottom-up approach to research, permitting the Deaf mothers' to share their stories in their preferred language. CBPR makes a space in which the community can direct the research, rather than having academics direct the research. Finally, minority communities historically are viewed as deficit populations, as problematic, as challenged and as in need of education from experts. Our study, suggests that Deaf mothers are very successful at breastfeeding. This is an opportunity to show the research world that the deficit paradigm has limited utility in scholarship. Community-based research can capitalize on the strengths of minority communities, revealing how they strategize around social barriers to breastfeeding.

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WELL ESTABLISHED: Deaf mothers who use American Sign Language (ASL) as their preferred language consider themselves part of a unique linguistic minority group with their own culture. Understanding culture is critical in supporting breastfeeding. Research on Deaf mothers and breastfeeding is nonexistent.

NEWLY EXPRESSED: Features of Deaf culture seem to provide breastfeeding support. In particular, the ASL sign for ‘struggle’ conceptualizes breastfeeding as a learning process that requires sustained effort and patience to be successful.

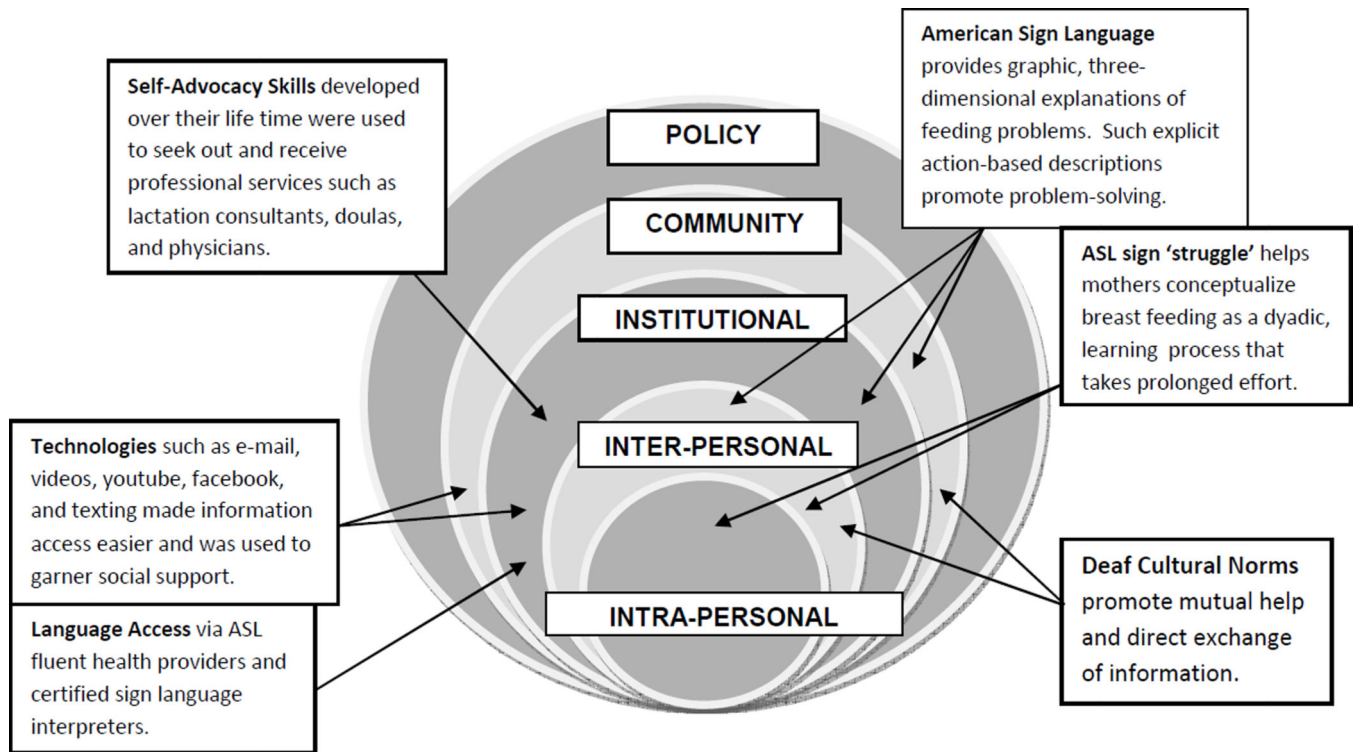


Figure 1. Identified themes interacted with one another and had multiple influences across levels of the social ecological model

Table 1

Participant Characteristics

Participant Pseudonym	No. of Children	Characteristics of Breastfeeding Child	
		Age	Breastfeeding Duration
Colleen	2	14 mo	9 mo
Amelia	3	15 mo	7 mo
Claire	2	13 mo	3 wk
Jane	1	9 mo	still
Joyce	1	5 yr	6 mo
Mary Ann	2	3 wk	still
Margie	2	2 wk	still
Lissa	2	19 mo	still
Claudia	2	3 yr	4 wk
Josie	2	2 yr	still
Marion	3	17 mo	3 mo
Susie	2	1 yr	still
Vickie	2	4 mo	still
Cynthia	2	14 mo	1 wk
Annie	1	19 mo	12 mo

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