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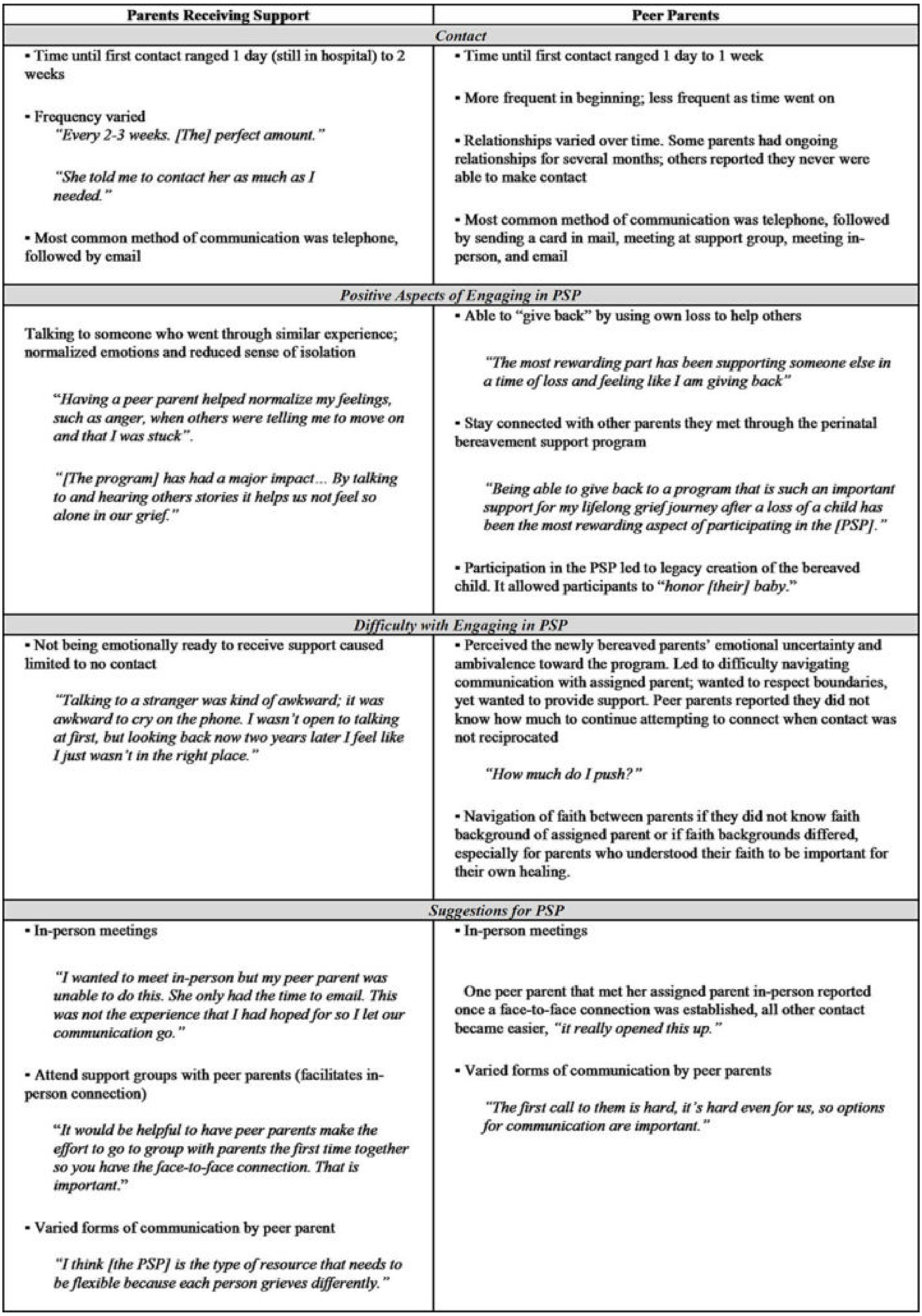
# Parents supporting parents: Development and evaluation of a peer parent program for perinatal loss

The loss of a pregnancy or newborn ( i. e., perinatal loss ) can be one of the most traumatic experiences parents can face. The most common type of loss is miscarriage ( i. e., loss occurring at < 20 weeks gestation ), which occurs in approximately 10% to 15% of clinically recognized pregnancies; stillbirth (i.e., loss at ≥ 20 weeks gestation) accounts for approximately 26,000 deaths; and, neonatal death (i.e., baby lives < 28 days) occurs in 4.04 per 1,000 live births.

Perinatal loss has been described as an “invisible loss,” meaning it is one that is not often shared or recognized by others. When people experience distressing events they often reach out to trusted others for comfort and support. However, perinatally bereaved parents have reported their grief is often not recognized by family and/or friends. Such an experience can leave parents feeling isolated and as if their distress is unwarranted. Additionally, these parents face a unique type of grief, one which involves the loss of expectations about the future. For these reasons, perinatally bereaved parents are well suited to being connected to a peer support program (PSP). PSPs provide a means of having lay peers with firsthand knowledge provide support to improve the care and outcomes for recently bereaved parents.

To provide an effective model from which other hospitals and support programs can develop perinatal loss PSPs, we conducted a program review of our PSP located in a mid-sized hospital in the Midwest. At the time of the study a total of 15 women and one man were trained as peer parents; 17 women were assigned to peer parents. The goal of our PSP was to offer recently bereaved parents another option for receiving support within our comprehensive perinatal bereavement program. The PSP did this by (a) recruiting and training qualified parents who could serve as peer parents; (b) formalizing peer connections by assigning a newly bereaved parent to a trained peer parent; and (c) having PSP coordinators maintain a supervisory role to peer parents by providing support, education, and evaluation throughout their PSP relationship.

Program review data suggested four overlapping themes emerged for the peer parents and parents receiving support. Both groups discussed the logistics of making contact with their assigned parent, their respective positive aspects and difficulties with engaging with the PSP, and suggestions for improving the PSP.



| Parents Receiving Support | Peer Parents |
|---|---|
| *Contact* | |
| • Time until first contact ranged 1 day (still in hospital) to 2 weeks<br>• Frequency varied<br>*"Every 2-3 weeks. [The] perfect amount."*<br>*"She told me to contact her as much as I needed."*<br>• Most common method of communication was telephone, followed by email | • Time until first contact ranged 1 day to 1 week<br>• More frequent in beginning; less frequent as time went on<br>• Relationships varied over time. Some parents had ongoing relationships for several months; others reported they never were able to make contact<br>• Most common method of communication was telephone, followed by sending a card in mail, meeting at support group, meeting in-person, and email |
| *Positive Aspects of Engaging in PSP* | |
| Talking to someone who went through similar experience; normalized emotions and reduced sense of isolation<br>*"Having a peer parent helped normalize my feelings, such as anger, when others were telling me to move on and that I was stuck".*<br>*"[The program] has had a major impact… By talking to and hearing others stories it helps us not feel so alone in our grief."* | • Able to "give back" by using own loss to help others<br>*"The most rewarding part has been supporting someone else in a time of loss and feeling like I am giving back"*<br>• Stay connected with other parents they met through the perinatal bereavement support program<br>*"Being able to give back to a program that is such an important support for my lifelong grief journey after a loss of a child has been the most rewarding aspect of participating in the [PSP]."*<br>• Participation in the PSP led to legacy creation of the bereaved child. It allowed participants to "*honor [their] baby.*" |
| *Difficulty with Engaging in PSP* | |
| • Not being emotionally ready to receive support caused limited to no contact<br>*"Talking to a stranger was kind of awkward; it was awkward to cry on the phone. I wasn't open to talking at first, but looking back now two years later I feel like I just wasn't in the right place."* | • Perceived the newly bereaved parents' emotional uncertainty and ambivalence toward the program. Led to difficulty navigating communication with assigned parent; wanted to respect boundaries, yet wanted to provide support. Peer parents reported they did not know how much to continue attempting to connect when contact was not reciprocated<br>*"How much do I push?"*<br>• Navigation of faith between parents if they did not know faith background of assigned parent or if faith backgrounds differed, especially for parents who understood their faith to be important for their own healing. |
| *Suggestions for PSP* | |
| • In-person meetings<br>*"I wanted to meet in-person but my peer parent was unable to do this. She only had the time to email. This was not the experience that I had hoped for so I let our communication go."*<br>• Attend support groups with peer parents (facilitates in-person connection)<br>*"It would be helpful to have peer parents make the effort to go to group with parents the first time together so you have the face-to-face connection. That is important."*<br>• Varied forms of communication by peer parent<br>*"I think [the PSP] is the type of resource that needs to be flexible because each person grieves differently."* | • In-person meetings<br>One peer parent that met her assigned parent in-person reported once a face-to-face connection was established, all other contact became easier, *"it really opened this up."*<br>• Varied forms of communication by peer parents<br>*"The first call to them is hard, it's hard even for us, so options for communication are important."* |

As a whole, the parents both providing and receiving support found the PSP to be helpful toward their healing. Such programs offer a much needed one-on-one approach to care that provides grieving parents with a normalizing experience.

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## Publication

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