A PANEL'S PERSPECTIVE

When a Baby Dies

We are pleased to provide a summary of the parent panel titled "When A Baby Dies: A Parent's Perspective During Crisis" at the 2015 NAPSW conference that was held on May 7th, 2015 in Vancouver. The panel was organized by Kathryn Barczi, Perinatal and Pediatric Social Worker, and Jens Locher, a bereaved father who founded the BC Childloss Support Network. There were five panelists from the province of British Columbia representing different health authorities, and losses at different stages and experiences. A short biographic summary of all panelists follows:

Charlene Chambers is the mother of three boys and one stillborn daughter. She experienced a loss at 20 weeks, two miscarriages, and a preterm delivery at 28 weeks.

Kerstin and Jens Locher are proud parents of three children: Marlon, Tobias and Thea. Marlon died two days after birth as a result of complications during delivery and Tobias was stillborn at 35 weeks of gestation. Thea was born four weeks early and is their only living child.

Meghan Neufeld is the devoted mother of one. Her son Ryker was stillborn in May of 2013 at 41 weeks gestation due to a double nuchal cord.

Darcy Smith is the mother of three beautiful children. Her second child and second daughter, Madisyn Claire, was stillborn in October of 2012 at 40 weeks gestation. She died only moments before birth after a healthy pregnancy. The cause of her death could not be determined.

All efforts were made to have a broad representation of experiences on the panel. However, because of the limited number of parents on the panel, it was not possible to achieve a representative and diverse sample with regard to ethnicity, religious and cultural beliefs. The presentation was purely about individual stories without the claim of these being representative.

Before the panel session started, Jens Locher asked the attendees to consider the current level of support for parents who are facing the tragedy of losing a baby. He used quotes from parents and health care professionals to show how differently the level of care is perceived. Many conversations in online forums show that parents have had vastly different experiences: some have felt very well supported in the hospital during this crisis situation; they have been invited to spend time with baby, take photos, and have received memory boxes or similar items. Others report leaving the hospital empty-handed.

Jens Locher then provided an introduction to support organizations, activities and events in Canada (see information boxes). Many of these initiatives have been the result of parents organizing support and services following their own experience of loss – trying to make a difference for other parents and honouring their own child in doing so. Of particular note are the various Walks to Remember[1] that happen between September to October, some of which exceed a thousand attendees; the Pregnancy and Infant Loss Awareness Day[2] on October 15 that is now recognized by a number of provinces and cities and supported by major landmarks such as Niagara Falls which light up in pink and blue on the day; and the Canadian Cooling Cot Campaign[3] which promotes usage of cooling cots at hospitals that allow babies to stay in the room with parents for a longer time period.

The panel discussion was organized into two broad categories: the time parents spend at the hospital between finding out about the death of their baby to being discharged, and the long-term challenges parents encounter after leaving the hospital. Although health professionals deal more directly with the first category, the panelists felt it to be very impor-

Canadian Support Organizations/ Resources (extract)

October 15 – Pregnancy and Infant Loss Awareness Day
Now I Lay Me Down To Sleep (NILMDTS)
Baby Gowns
Pregnancy and Infant Loss Network (PAIL)
Bereaved Families of Ontario
Tiny Hands of Hope
Angel Whispers
HEARTS Baby Loss / Briar Patch Centre for Grieving Families
BC Childloss Support Network
Mothering Your Heart
Empty Arms, Healing Hearts

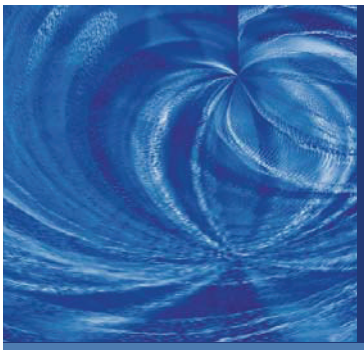
Canadian Walks to Remember

- Alberta
  - Calgary
  - Edmonton
  - Grande Prairie
  - Sherwood Park
- British Columbia
  - Kelowna
  - Dawson Creek
  - Fort St. John
- Manitoba
  - Winnipeg
- Nova Scotia
  - Halifax
- Ontario
  - Toronto
- Saskatchewan
  - Weyburn
  - Regina
  - Carnduff

For event dates and all details please visit http://www.october 15.ca/category/events/.

tant to highlight some of the difficult experiences they encountered later. While many improvements have certainly been made with regard to support at the bedside, long-term support appears to be much more challenging.

A brief summary of topics and issues raised by the panelists follows.



Parents want options — naming their baby, time spent at the hospital or at home, mementos of the birth

At the hospital

Importance of a name

All panelists found it very important that health professionals refer to their baby by name. Suggestions were to ask parents if they have picked a name for their child and if they should be using the name in the hospital. "My child has a name, specially chosen for him or her; please call my child by the name we have chosen." Some of the parents shared being very upset when the name tags for their baby stated "stillborn" or "baby boy," even though they had named their baby. They felt that this diminished the importance of their child. Medical language posed another challenge for panelists who felt that terms like "fetus" or "product of conception" marginalized their loss of a child.

Importance of time

The importance of giving parents as much time with their baby as they need was stressed by all panelists. The option of offering the parents more time can be important before the baby is born. Depending on the situation the panelists felt that parents should be given the option of not rushing to induce delivery immediately after they receive the news that their baby has died (if medically appropriate). Parents should be given the time to be able to prepare for meeting their child, e.g. to organize time for family to come meet their child, getting a photographer to the hospital, fetching some clothes to dress baby in or similar. One panelist shared that it was very important to her to go home for the afternoon to pack some special outfits for their baby and go for a last walk on the beach with the baby.

All panelists stressed that once the baby was born the time spent with their baby was extremely precious and important to them: "This is the only chance we will have to spend time with our child. Encourage us to bond with our child - holding, bathing, diaper change…"

A panelist asked the audience if they encourage parents to take their baby home if this seems possible. Different regulations may exist in each province/state about this possibility, but many hospitals do not seem to mention this option to parents. Giving the many stories from parents about the traumatic experience of coming home without baby and their expressed wish that they could have brought baby home, the panelists felt that this should be explored more by social workers.

Mementos / Pictures

Now I Lay Me Down to Sleep was mentioned by all panelists as an extremely valuable service that all hospitals should be aware of and consider using. Given the importance of photography, as this is the only chance to take photos of the baby ever, all panelists stressed that pictures really are some of the most important items they cherish. Panelists cautioned the hospitals about replacing a professional service with digital cameras purchased and given to staff. Although it can work and be very important to have a digital camera ready, especially if a volunteer photographer is not available or the situation is very time-sensitive, it carries a lot of risks as the quality of professional pictures can be far superior.

The panel shared these two stories from their network:

"Today was very tough for me. Our local hospital does not reach out to any volunteer organizations. During our time there the nurses took my daughter for pictures. They assured me they would be beautiful. I myself took many photos, which I am very glad I did and they came out really well. So it's been a couple of months and her picture came in the mail today. I was shocked when I opened it, really I was. They did not at all capture the beauty of my daughter. Their photo looks like an old fashioned hospital photo, I almost don't recognize her. It made the hurt so much worse." Mother, Massachusetts, Feb 2015).

"When we went to pick up additional items of our son that the hospital had kept (despite us saying we would not want these, which we are now glad they did anyway), we received a CD with additional pictures. These were taken after we had said our farewells. We were surprised to be receiving additional photos of a time we were not with our son." Father, British Columbia, March 2015.

The panelists felt that hospital staff should encourage the parents to take pictures of their baby. However, depending on the situation some parents may decline the offer to take pictures, which sometimes leads to regrets later. The suggestion of the panel was for the hospital to offer to take the pictures and to keep them so that parents have the choice later if they do want to view these.

Other mementos that panelists received were the measuring tapes used to do the initial assessment, the blankets or clothes the baby wore, hand and foot prints or moulds of the baby's hands or feet (sometimes turned into jewelry), a lock of the baby's hair. Social workers and or hos-

pital staff should be able to assist with creating these mementos and should be aware that some mementos might be time-sensitive.

What to say/not to say

The panelists agreed that this was very difficult to answer as it probably is different for every parent, and what may feel supportive to one parent, may not feel the same way for another. Consensus was that people should not feel the need to say something just for the sake of saying it if it may not be perceived as genuine by the parents. Topics of a religious nature may be very sensitive, e.g. referring to the baby as an angel. Insinuating that the baby died for a reason may be a trigger for many parents as well. Statements that were perceived negatively included ones that were dismissive of or downplayed the pain of the parents or the importance of the existence of their child, such as "you can have another one." All panelists said that anyone genuinely saying "I don't know what to say. I am sorry for your loss." was perfectly acceptable.

Acknowledgement

Acknowledgement was identified as a very important topic by the panelists. It extends to multiple areas, such as acknowledging the existence of the baby as an individual person, the birth experience, and the parents as parents. Parents should be offered the same choices as any other parents of children born alive. "I nurtured my child in my womb, and then birthed her. She lived, and is an important member of my family. Acknowledgment of her life is so important."

The maternity ward

Panelists hope that hospitals recognize the challenges maternity wards pose for bereaved parents. The trauma of parents can be increased by staying on the maternity ward where they witness happy families who delivered healthy babies, hear the screams of newborns, or even stay in rooms that are designed for families with their living children. One mother was put into a recovery room together with a mother who had just given birth to a child who was raving about how beautiful the baby was. Although there may be limited resources available, specially designed bereavement suites with sound-insulation seem to be becoming more common.

Providing choices to the parents

As most parents never even consider that their baby might die unexpectedly, the shock and trauma make it very difficult to think clearly in such a situation. Parents are very dependent on the guidance of health care providers who can bring up options they otherwise might not think of in their state of mind. Several of these options have previously been mentioned and include pictures, bathing and dressing, taking baby home, etc.

Long-term challenges

Leaving the hospital

Having to say farewell to baby and leaving the hospital can be a very traumatic experience as it marks a time when parents have to go back into the regular world. Panelists described that their world had shattered, but outside the hospital everything continued in its normal routine which was a difficult situation to grasp. There may not be much support the health profession can offer in this situation, except perhaps talking through some of these potential challenges with parents before they leave and reassuring the parents that they can receive support. Surprisingly, panelists reported from their own experience and based on conversations with other bereaved parents that very few resources are provided to parents before they leave. Panelists suggested that it would be fantastic if more resources, such as support groups available in the local area, specialized counseling for child loss etc., were made available.

The first few weeks

Panelists described that they received follow-up calls from social workers and nurses who did not know what had happened to the family. This led to difficult and awkward conversations. It should be ensured that all care providers who get in touch with the family have the correct information. Moreover, the first few weeks may feel like an onslaught with many people wanting to show their support, calling and asking how to help. Although very well meant, this can be overwhelming to parents. A suggestion was for the hospital to ask for a close contact of the family who they could reach out to in order to help that person to prepare the support network, e.g. in the form of organizing a meal train, or mediating between family and friends. Flowers and cakes arrive in abundance in the first few weeks, when a healthy meal may be more helpful. Moreover, after the intense initial phase of a few weeks contact often diminishes, leaving the parents feeling even more isolated and fearing that everyone else may have moved on.

Loss of community/social connections

The loss of a child can be extremely isolating. People often don't know what to say and may avoid contact with the family, and social connections and friendships may shift dramatically after the loss of a child. It does not seem that there are any social programs in place to bridge this gap which makes it even more important to connect parents to a network of support, such as other bereaved parents. Reach out, and help parents network with other parents, or direct them to resources.

Religion/Faith

This topic was mentioned throughout the panelist conversation. It highlighted that there are vastly different belief systems and that it may be dangerous to project one's own belief system onto another family.

Multiple losses/Pregnancy after loss

Due to time limitations the topics of multiple losses and pregnancy after loss could not be addressed. These are very important topics though as proper support from health care providers during these extremely challenging and emotional events can make a huge difference for families.

During the question period the following questions were addressed:

How do the panelists feel about perinatal social workers making a follow-

up call about six weeks after discharge?

A genuine phone call was perceived as helpful by all panelists. However, questions such as "how are you doing?" can be challenging to answer for parents. Some parents cannot even articulate what they may feel, or the question seems rhetorical because the answer is very apparent to all bereaved parents. An easier question to talk about might be "what have you been doing in the past few days?"

The panel mentioned that mementos are very important. An audience member expressed concern about potential challenges in storing lots of items for various families and asked how long they should be kept?

If space is a problem, it may work to store items in a hanging cabinet in sleeves instead of using actual boxes. Moreover, digital images could easily be stored on a shared network drive or similar and archived for a longer time. Panelists felt that six months would be very helpful, if possible even longer for 12 months.

Should health care providers encourage siblings to spend time with the deceased baby?

Two panelists commented that it was very important to them. "One of my biggest regrets was not letting my son see his sister. He still brings it up to this day four years later." Another story was shared where a hospital helped a family create mementos that included the siblings by creating hand prints of all their children on a single page.

All panelists would like to express their deep gratitude to the conference organizers for the opportunity to share their stories and personal experiences.

In loving memory of Faith Tien, Madisyn, Marlon, Ryker and Tobias as well as all other babies who died too soon.

1. http://www.october15.ca/category/events/
2. http://www.october15.ca/about/
3. http://www.october15.ca/canadian-cooling-cot-campaign/

social action committee

Sometimes, when a mental block hits, you have to turn for others for help. Well, I have hit my block with social action articles. I am centered in a small area in southern Indiana, away from the big cities and all the government powers that tend to make the big decisions. I read my local paper, from print and on the iPad, hitting the highlights that pertain to my interest. Now, if someone calls and tells me to look at this article or that article, I will. This is what I do when someone sends me an article to look at or tells me about something happening in their state or area, I look at it, I read it, and I think about it. Oh wait; this has only occurred a couple of times.

Tiffany Hanff, from California, was so kind to send an email about an article in the Sacramento newspaper about a bill the State of California passed so that undocumented children would receive Medi-Cal. The California Senate approved health care for undocumented immigrants, SB 4. I read the article, and it is actually for both adults and children to receive care. Indiana has the same plan thru Emergency Medicaid, and I bet many other states do as well. What a wonderful country we live in that stands up for the care of children, no matter where they or their parents call their true home. Social workers tend to be the Medicaid benefit for others, in real life issues.

Stay with me on the above point. State or Federal benefits are for those individuals in need of insurance, food, clothing, housing, income etc. Social workers, not just perinatal social workers, guide families to these same services. We are the Federal and State benefit to our agencies, hospitals, schools, clinics, universities, private offices etc. We are the ones to aid those in need and make their lives more bearable or comfortable. Well, we attempt to make things more bearable. Sometimes we can't make things come together, but it doesn't mean we failed. Just means we have to try a different approach. Approach might just be a fancy word for Social Action, among other descriptions. The State of California didn't have to adopt a policy to cover undocumented children or adults, but someone came forward, a concerned someone, and introduced the bill because so many families were coming into their state and needed care. This change did not happen overnight – most social action events do not – but it happened.

So, as I always seem to, I'll change my request; what can we as perinatal social workers do to make our families a little more happier, in control and comfortable? I wonder if we presented ourselves as some of our presidential candidates, if our platform might read like this. "I promise to make all NICU parents more comfortable in my hospital's setting by supporting education of the nurses and physicians to realize that parents want to be more involved as part of the treatment team. I promise to "tell it like it is" because it's not always business first. I promise to call out those staff members that are not pulling their weight in the NICU and demand equal time with your child from each therapist, nurse, respiratory therapist physician, chaplain, dietician, pharmacist and social worker. I promise to have three meals a day for families, in order to keep you here, as well as family accommodations. Breast pumps for every family. Promises we can't always keep, but sound good when talking others.

Sometimes Social Action projects sound far-fetched and unreachable, but through hard work and willingness to keep going forth, it clicks. So again, what is something you see that needs our support for our smallest and sickest of babies? What can our goal be to help those families that need more from their state? I call for your help. Thank you.

Respectively submitted,
Beth Paul, LSW