Raising the bar: development of a perinatal bereavement programme

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Abstract

The care a family receives at the time of perinatal loss can have a significant and lasting impact, hence it is important for healthcare providers to offer quality care that will meet the family's needs. Our hospital embarked on a journey to develop a perinatal bereavement programme that would give compassionate and excellent care to all families who experienced perinatal loss at any time during their pregnancy. Components of our bereavement programme include leadership, administrative and financial support, communication, well-educated and supported staff, and a process for individualised care. A perinatal bereavement programme can help institutions, large or small, to provide quality care for bereaved families and help them through this difficult experience. The purpose of this article is to discuss hospital-wide bereavement care, both on a large scale, detailing the specifics of programme development, and on a smaller scale, individualised care for families.

Key words: ● Perinatal loss ● Bereavement care ● Nursing care ● Compassionate care

Our hospital embarked on a journey to develop a programme that would give compassionate and excellent care to all families who experience perinatal loss at any time during a pregnancy or soon after birth, and in any area of the hospital. Our definition of excellent bereavement care is to give care to a bereaved family that meets their needs and is consistent with international perinatal bereavement standards (Association of Women's Health Obstetric and Neonatal Nurses (AWHONN), 2014; Donovan et al, 2015; Sands, 2016).

Last year we met a family that has changed us forever. They shared their joy and heartache as they met, loved and said goodbye to their daughter, Anne. Anne had multiple birth anomalies and it was determined that Anne would be unable to live after birth. Anne's family chose palliative care and we began a journey that taught us many things: to follow our patient's lead, to remain flexible, to be willing to give of ourselves, and to watch and learn how to celebrate Anne's brief, but important, life. The purpose of this article is to detail the specifics of programme development, while also discussing individualised bereavement care for families.

Background

We realised, when working with Anne's family and others, the prevalence of perinatal loss. An estimated 2.6 million third-trimester stillbirths occurred in 2015 worldwide (Lawn et al, 2016). MacDorman and Gregory (2013) found that in the US alone, 1 million fetal deaths occur each year. The frequency of perinatal death demonstrates the need for healthcare providers and agencies to be prepared to offer quality bereavement care.

In the US, a miscarriage is defined as loss of a fetus/baby before the 20th week of pregnancy, and a stillbirth is loss of a fetus/baby after 20 weeks of pregnancy (Centers for Disease Control, 2017). Perinatal death and perinatal loss refer to the loss of a fetus/baby at any gestational age or the loss of a newborn before the age of 7 days. Perinatal bereavement care is the care given to families who experience this type of loss.

Nursing, midwifery and medical research and literature overwhelmingly support the need for good, well-planned, compassionate care to families who experience the death of their baby (Hughes and Goodall, 2013; Ilse, 2013). Steen (2015) found a continued need to increase the standard and consistency of perinatal bereavement care worldwide. Parents voice frustration at the

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unfairness of making decisions based on insufficient information provided by professionals (Burden et al, 2016).

Many organisations have written standards of care for bereaved families and their newborns in the hope of improving care practice (American College of Obstetricians and Gynecologists (ACOG), 2009; Sands, 2016).

Van Aerde (2001) shared important actions to take during and after the death of a baby. AWHONN declared that 'nurses play an important role in bereavement support, and this nursing care should be defined, measured, and benchmarked' (2014). Many organisations, such as Sands (2016), support the role of the nurse in providing emotional support for parents and helping them create memories (ACOG, 2009; AWHONN, 2014). Sands, which stands for the Stillbirth and Neonatal Death Society, supports those affected by the death of a baby and works with health professionals to guide, change and improve care.

Burden et al (2016) reported that stillbirth is a life-changing event with psychological, physical and social costs. Hughes and Goodall (2013) stated that the care a family receives at the time of loss can have a significant and lasting impact, hence it is important for healthcare providers to offer quality care that will meet the family's needs. Donovan et al (2015) detailed specific bereavement services offered to bereaved families in perinatal hospital settings. Many of the services mentioned in Donovan's article support the discussion that follows regarding necessary components of a bereavement programme.

Donovan identified the need for programme components, such as dedicated funding, a programme coordinator and the need for education and support of staff. She also describes the importance of effective communication, continuity of care, guidance and support of families (Donovan et al, 2015). The Sands guidelines describe similar components of good communication, holistic person-centred care, the importance of staff support and training and follow-up care for families (Sands, 2016). Other essential components identified as being critical for a bereavement programme include leadership, administrative support and individualised care of families (Gibson et al, 2011; Steen and Ilse, 2015).

Based on nursing literature and previously mentioned standards of care, the following components were identified as being critical for our bereavement programme: administrative and financial support, leadership, education and support of staff and coordinated, individualised care of families. These components served as a template for programme development.

Anne's family

Anne and her family

Our hospital, in the Minneapolis area of Minnesota, with 4800 births per year, may have resources and needs that differ from other birth centres; however, all birth centres must be able to provide bereavement care to their patients. Our hospital-wide programme supports insured or uninsured women suffering a loss, including early or late miscarriage, stillbirth, neonatal death and palliative care.

Bereavement programme components

Before the development of the bereavement programme, there was little formal policy or procedure for perinatal loss care. Fifteen nurses, who worked at the birth centre before and after programme development, were asked to answer a few questions regarding the above-listed programme components. Of this group, 93% believed that no programme components were present before programme development; one nurse identified the component of individualised care as being present prior to programme development; and 100% believed that all components were present after programme development.

Administrative and financial support

It is critical that administration supports the development and ongoing financial assistance of a well-planned and implemented programme (Jonas-Simpson et al, 2010; Steen and Ilse, 2015). Budget items needed for a programme include full-time equivalents for bereavement programme

'A birth plan can decrease anxiety by ensuring that wishes are clearly communicated and can give a sense of control in a situation where many things may feel out of control'

Anne's family

Anne's parents bathing her shortly after her birth

leadership, resources for 1:1 nurse-to-patient staffing, financial support for memory-making items, and educational and support resources for both staff and families (Gibson et al, 2011; Donovan et al, 2015). Families have donated money and we have received grants to create our 'Bereavement fund.' Parents, organisations and our 'knitting grandmas' donate items to give as memory-making gifts to families. Financial support at the highest level, however, comes from our hospital administration, which realises the need to care for bereaved families by supporting the nurse navigator role, allowing for bereavement programme leadership and for coordination of care. Administration also continues to support adequate staffing to ensure high-quality bereavement care.

Leadership

The nurse navigator is the person designated to coordinate perinatal bereavement care at our hospital. Gordon et al (2015) found that the nurse navigator role not only facilitates communication among the team, but also helps to meet the needs of the family. Whether institutions use nurses or social workers for this role, what is essential is to have an individual whose job description includes coordination of the bereavement programme. When leadership is lacking, even in well-developed programmes, programmes may begin to deteriorate because of daily demands (Donovan et al, 2015).

All areas of our institution that work with perinatal loss, such as emergency services, surgical services and the birth centre, are included in our programme. At times, we have found that a policy may need to be re-examined. A distraught parent, who had suffered many miscarriages, contacted us after learning that at another hospital she could not take home fetal remains after a procedure. Our hospital had recently changed the policy regarding the handling of fetal remains after a change in a state statute. Hughes and Goodall (2013) stated:

> **'Practices, policies, and guidelines need to be reviewed in order for us to question why things are done as they are and ensuring that quality and current evidence is the basis for our care'**

The change in our practice allowed this parent to take home her fetal remains, which honoured her legal rights. Many families now choose to do the same when informed of this option.

Table 1. Perinatal loss competency

Critical elements of performance	Met before education (%)	Met after education (%)	Not met (%)
Demonstrates compassionate care and use of presence	90	98	2
Verbalises helpful words to use with bereaved parents	63	83	16
Describes the 'rights of parents' (Share)	36	70	30
Verbalises an understanding of grief support and resources on unit/ hospital (i.e. chaplain, mementoes, camera, written materials, and support group)	61	90	10
Verbalises an understanding of perinatal grief as a life-long parenting experience	81	96	4
Verbalises and demonstrates components of memory making activities including quality bereavement photography.	60	87	13
Verbalises an understanding of perinatal palliative care and advanced directives	46	79	21
Verbalises the legal importance of calling Life source within 1 hour of baby's death	90	94	6
Verbalises an understanding of the options of autopsy and/or genetic studies with parents: • less than 20 weeks • greater than 20 weeks	35	56	9
Verbalises an understanding of parent options related to disposition and can discuss in an honest and sensitive manner: • less than 20 weeks • greater than 20 week	41	51	8
Demonstrates ability to document in EPIC and on bereavement forms	41	39	20
Verbalises cultural and religious needs of the bereaved family	76	11	13
Verbalises an understanding of the importance of self-care and utilising support resources and mentors	79	18	2

Critical elements are taken from Van Aerde 2001, 2015; AWHONN 2014; Sands 2016

Education and support of staff

A critical component of a bereavement programme is the training, support and mentoring of staff that is based on comprehensive international standards, protocol, and policies (ACOG, 2009; AWHONN, 2014; Sands, 2016). Comprehensive education of staff with clear guidelines is essential (Jonas-Simpson et al, 2010; Gibson et al, 2011). Nurses' positive attitudes about caring for families experiencing perinatal loss have been associated with previous bereavement education and supportive colleagues (Hutti et al, 2016). In our programme, a self-identified bereavement team of nurses is educated and mentored, which allows us to provide around-the-clock trained staff. Since programme development, all new hires to the labour and delivery area receive bereavement education.

Table 1 details a competency that is used to measure ongoing bereavement educational needs and programme effectiveness. At present, there are no universally accepted global standards of bereavement care. The competency's performance elements are recommendations taken from a number of international sources regarding adequate perinatal loss knowledge for healthcare professionals (Van Aerde, 2001; AWHONN, 2014; Sands, 2016). During a recent staff education day, 49 nurses completed the competency. All nurses had worked on the labour and delivery unit of the hospital for between 1 and 7 years. Before the session, they identified, with a red pen, which performance elements they met. After the education session, they identified, with a black pen, which of the elements they now met. Not all nurses addressed each element. Before the education session, many nurses indicated that they met the performance elements of demonstrating compassion, addressing cultural and religious needs and the importance of self-care. After the education session, most nurses indicated that they met all performance elements, showing effectiveness of the education session. Nurses identified needing more education related to elements of palliative care, such as advanced directives and documentation in the electronic record.

Table 2. Parent evaluation of care

Department at the hospital where care was received	Emergency services (n=3) (%)	Surgical services (n=12) (%)	Labour and delivery (n=7) (%)
Were you offered written materials?	100	83	86
Were they helpful?	100	58	57
Were the keepsakes and activities of making mementoes helpful in creating positive memories of your baby?	100	100	100
Did you receive a follow up phone call or card from our staff after discharge?	100	92	100
Was it helpful?	100	92	100
Were you able to develop a birth plan? If so, was the plan followed?	0	0	70
• Was it helpful?			70
I felt I could talk openly with nurses and physicians	100	100	100
I felt listened to	100	92	100
Nurses and physicians provided a calm atmosphere	100	100	100
Nurses and physicians were compassionate	100	100	100
Nurses and physicians helped my partner and family	100	92	100
Nurses and physicians helped me	100	92	100
Nurses and physicians offered resources	100	83	100
Nurses and physicians were concerned about me	100	92	100
My fears were discussed and addressed by staff	100	92	86
Please tell us more if you wish			

Coordination of individualised care

Birth planning

The final component of a successful bereavement programme is a process that offers care to every family from the time of their identified loss and throughout their bereavement journey (Steen and Ilse, 2015; Sands, 2016). When possible, slowing hospital admittance allows for sharing of information, which can assist families as they prepare for the birth of their baby. This time may result in parents feeling less shock and more control at this very difficult time (Ilse, 2013). Kuebelbeck and Davis (2011) stated:

> **'A birth plan can decrease anxiety by ensuring that wishes are clearly communicated and can give a sense of control in a situation where many things may feel out of control'.**

At a time when parents may feel overwhelmed, they tell us that birth planning allowed them to prepare for the many decisions that they needed to make. One father commented:

> **'After finding out that our baby had died in utero, we were devastated. The two days of planning before our baby was born, allowed us to make wonderful memories that otherwise would have been memories that we would want to forget.'**

Anne's family commented:

> **'Being told we had time to breathe, to take the time we needed to plan and make decisions, was a gift. We would have gone down a path that we would have regretted, rather than allowing Anne to decide the time of her birth and death. This allowed us precious time with her, before her birth and in the days following her death.'**

Birth plans are used with families on diagnosis of a fetal death or a lethal anomaly. On occasion, it may not be possible to develop a birth plan or the plan may be very brief. It may be a hard copy, used as a guide while directly caring for the family or, when time allows, it may be prepared in advance and placed in the patient's electronic record. The plan allows families an opportunity to ask questions and understand options and choices. Birth planning often includes a discussion of the involvement of extended family and friends, sibling care, memory-making, faith traditions, ceremonies, discussion of testing and autopsy, handling of the baby's body and funeral planning (Kuebelbeck and Davis, 2011; Steen and Ilse, 2015).

All families who have experienced a loss in any area of our hospital receive a follow up 'Evaluation of care' document. This document

reflects our programme goals and policy, and is another way to evaluate our programme. Parents receive a survey in the mail 1 month after their loss. We request that they return the survey in an included envelope and may sign their name or remain anonymous. *Table 2* includes responses from 22 families who returned the evaluation over a 1-year period. Results show that when birth planning was possible, 70% of families not only found value in having a plan, but also felt that the staff followed the plan. Evaluations also showed that all parents believed that the nursing team offered compassion and guidance during their hospital stay.

Birth experience

One day, the nurse navigator received a call from an obstetrician who had diagnosed a term stillbirth. The nurse navigator was able to meet the patient, Maria, and her family in the clinic, enabling her to do some initial birth planning and offering support. (Maria and her family members' names have been changed to respect their privacy.) When possible, we encourage families to take time to think, prepare and plan for the birth. Maria and her husband insisted on coming to the hospital that evening to begin the birth process immediately. Maria, as with all of our families that have experienced loss, was encouraged to include any family members and friends who would like to meet the baby. Some parents may find this surprising and may not welcome others into this experience; however, Maria and her husband chose to surround themselves with supportive family.

Sibling involvement

Families are commonly confused about how to explain their baby's death to their other children and how to include them in the process. We remind parents that they know their children best and we try to provide the tools and resources to support their decision-making (Van Aerde, 2001). Maria chose to have her 5-year-old daughter, Clara, involved during the entire birth experience. Clara cried along with the rest of the family and stayed very close to Maria. Clara continues to talk about her deceased sister and Maria is very happy that this baby continues to be a part of their family.

Memory-making activities

Families have memory-making opportunities and typically accept pictures, ceramic moulds and footprints, a lock of hair, a birthstone key ring and a hand-knit blanket, all housed in a memory box. We use photographers and find pictures to be a wonderful gift to families. Post-mortem bereavement photography can be valuable during the crisis of a baby's death (Hughes and Goodall, 2013). Maria chose to involve a photographer and had many pictures taken by family members. Clara helped the nurses to make footprints of her sister and also made prints on a clay pot with her own and baby Emilia's hands. Parent evaluations showed that memory-making was highly valued by all families. One parent responded: 'I especially liked the butterfly keychain. It provided me with some tangible comfort in the following weeks.'

Spending time with the baby

Being with a deceased baby after birth can be a frightening time for parents. They may need a great deal of support as they determine how much time they want to spend with their baby (Kuebelbeck and Davis, 2011; Warland and Davis, 2011). Parents are encouraged to stay with their baby for as long as they desire, making memories and allowing an opportunity for siblings, family and friends to meet the baby. Maria and her family chose to spend 2 days with baby Emilia. They bathed and dressed her, an opportunity for parenting.

During the hospitalisation, additional members of our bereavement team may participate in the care. Chaplains are part of our team and visit every parent who has lost a baby. The chaplains not only meet spiritual needs, but are also available for rituals or faith traditions that the family may desire. Maria's pastor was available to them in the hospital and they began funeral planning. Some families choose to meet their child only briefly, and, occasionally, a family will not want to see their baby at all. If the family chooses not to see and hold their baby, we respect this decision (Sands, 2016). Based on international bereavement standards, we continue to offer the opportunity to see the baby and keep the baby on our unit in a secured bereavement room (Van Aerde, 2001; Warland and Davis, 2011). We have found that with time, a parent may reconsider their initial decision. Studies have determined that seeing and holding a stillborn baby can be helpful for the parent's grief process (Kuebelbeck and Davis, 2011; Warland and Davis, 2011).

Autopsy and handling of the baby's body

Patients need to be informed of their options in regard to autopsy, testing procedures and handling of the baby's body. Options of hospital and private disposition are explained to the

family. Funeral homes provide cremation and burial services for a reasonable price or free of charge for families with financial hardship.

Leaving the hospital and saying goodbye

Families have traditionally determined when they were ready to send the baby's body to the morgue. Some families want to leave their baby in a nurse's arms. Families often tell us that they do not want their baby left alone, so we now offer parents the option of having the funeral director collect the baby directly from the room, bypassing the morgue. Our goal is that when the family leaves, they can say goodbye to their baby in the way they desire. Maria and her husband had a very difficult time saying goodbye to Emilia. With tears, they chose to leave her in the arms of a nurse who cared for them during the hospitalisation.

Follow-up care

Parents who have experienced a perinatal loss at our hospital receive a follow-up phone call and cards soon after the birth and again, after 3 months. Our parent evaluation revealed that 95% of respondents received a phone call and 85% found it helpful. Of the families who experienced a loss in our hospital, 91% received written support materials, and 70% found them to be helpful.

We offer a monthly, face-to-face loss support group for those who desire ongoing support. At times, members meet outside group time, creating their own support network. Parents who experience loss can develop resilience and new abilities (Burden et al, 2016). Our desire is to help families find resources for continued healing. An annual memorial service has been an effective way to re-connect with families and offer continued support and encouragement. At this service, through music and words, we offer a short message of hope and a time of reflection. Clara was able to plant a bulb and float a candle this year as she remembered her sister, Emilia. Donovan et al (2015) found that these types of services have been helpful to families that have experienced perinatal loss. Parent evaluations lead us to believe that the goals and components of our programme have met the bereavement needs of many families.

Barriers

Identified barriers to a bereavement programme include: a lack of financial support; challenging staffing issues; the need for ongoing education due to staff turnover; and the absence of a designated leader (Donovan et al, 2015).

A lack of leadership is a common barrier for many programmes. An individual who is responsible for advocating and directing the programme can work with providers to allow bereaved families to celebrate the lives of their babies (Donovan et al, 2015). Without a designated leader, programmes may flounder.

On occasion, staffing issues make 1:1 nurse-to-patient ratios impossible. This ratio is important because nurses may find it extremely difficult to meet the needs of the bereaved family while caring for another family who is celebrating a new life. Nurses may not be able to 'flip their emotional switches' (Hutti et al, 2016). At times, nursing leadership may need to be reminded of the complexity involved in caring for families that have lost a baby.

Staff turnover can lead to a shortage of trained nurses. New staff must be trained and mentored in bereavement care. Cumbersome paperwork seems to be an obstacle and a cause for confusion. A bereavement binder with clear directions for completing the required paperwork has been found to be helpful. Infrequently caring for families that have experienced loss may lead to more uncertainty in this area. Nursing leaders on each shift maintain bereavement competency in the hope of helping newer bereavement nurses feel more supported with resources.

Literature suggests that offering compassionate care, rather than being detached from the parent's experience, is extremely important for grieving families (Hughes and Goodall, 2013). Providing this type of care can, however, be very emotionally draining for the nursing staff and other providers (Jonas-Simpson et al, 2010; Steen, 2015). Nurses may simply find that caring for bereaved families is too difficult for them.

Following a challenging event on the unit, the chaplains facilitate debrief sessions and times for renewal. They also place 'care baskets' in the nurse's lounge that contain candles, stones and candy treats, accompanied by a note expressing care for the caregivers.

Cultural beliefs influence a family's response to perinatal loss. Our lack of awareness of these beliefs can be a barrier to compassionate care. Careful assessment and planning can provide families with individualised, culturally specific care (Shaefer, 2010; Hughes and Goodall, 2013; Flenady et al, 2014). Flenady et al (2014) stated that:

> **'Different interventions will be required for different settings and cultural groups, but essential ingredients of quality care include a**

deep respect for the individuality and diversity of the parents' grief and respect for the deceased child'.

When a family chooses an uncommon approach to the loss of their baby, we must remember that each family experiences loss in their own way.

Conclusion

Since development of our bereavement programme, members of staff have verbalised their increased confidence in caring for bereaved families owing to the education, support and mentoring that they have received. They have found birth planning to be helpful as it allows them more time to spend with the family. One nurse commented that the bereavement programme has allowed her to be at her best during the most rewarding yet painful patient care experiences. Another nurse believes that the bereavement programme has enhanced her nursing care as she uses skills of counselling, teaching and providing emotional and spiritual care to the entire family.

When Anne's father returned to our hospital to deliver cupcakes on the 1-year anniversary of her birth, he was surprised to hear a nurse greet him with the words: 'You're Anne's dad!' He was touched as he realised that he was known as Anne's father. Anne's legacy continues to touch lives. Her parents' love and willingness to share her story has ministered to many other parents and staff.

Every family deserves to remember, grieve and celebrate their baby in their own way. This, to us, connotes success. It has been an honour to know and care for Anne, Emilia and many other very special babies. Despite barriers and challenges, let us persist and call on all providers and institutions to care for and support families through this difficult journey. IJPN

Key points

- **Bereavement programmes help to provide quality care for families**
- **Nurses need to be trained, mentored and supported in bereavement work**
- **Each bereaved family is unique and deserves individualised, comprehensive and compassionate care**

Conflict of interest: *None*

Acknowledgements: *The author thanks Faith Zwirchitz for her unwavering belief in, and support of, this very important work.*

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Continuing professional development: reflective questions

- **Why is it important for healthcare providers and healthcare agencies to be prepared to offer quality bereavement care to families who have suffered a perinatal loss?**
- **What are important bereavement programme components for comprehensive, yet individualised bereavement care?**
- **What types of bereavement care interventions do parents identify as being helpful to them?**
- **A 5-year-old sibling of a stillborn baby wants to come to the hospital to meet her sister. What would you advise the family?**

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