DEALING WITH FETAL DEMISE
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Allow me first to thank the organizers for asking for a reflection on the subject of fetal demise; and to be a member of the faculty for this conference. It is an honour at best, a challenge for certain. I mention with gratitude Marion MacArthur, chief librarian at the QEH hospital here in Charlottetown, who with unfailing grace, directs me to and secures the latest research material available ... not only for today but in other subject areas, especially those relating to spirituality and wellness. I also acknowledge the mothers and fathers of those children who have not seen the light of day. We shall discover in the next short while the effects of perinatal or neonatal loss and the part each of us has in the process. My professional mind set is that of a spiritual care provider. In your own way, many of you may have an operational spirituality in your own work activity.

You should know that there is a paucity of research and reflection from the perspective of sonography, which is possibly why it is on the agenda. The following talk is not a scientific research paper, but a practitioner reflection which has the ultrasound piece as one of the critical moments in a longer continuum. It is important to understand the larger picture so we can appreciate our own roles within that. The referenced articles have been carefully selected. Those articles would have further citations should you be interested.

1. INTRODUCTION

Barbara Pender was just starting to show when her baby's heart stopped. Maybe the world didn't know she was four months pregnant. But she did. And she was determined to deliver the unborn baby, and take other steps to dignify its brief life, she said. Pender laboured in silence for 13 hours in a hospital maternity ward, until a boy, no bigger that the cup of her hand, slipped almost undetected from her womb onto a bed sheet. She held him. Named him. Blessed him. And buried him.... Her husband Don and two daughters often join Barbara at a grave no bigger than a boot box. Pender is among many parents who've suffered the loss of a child before birth. One in four of all pregnancies ends in miscarriage – before 20 weeks – or stillbirth – after 20 weeks.

The death of a perinatal child is heart-rending and a tragedy. The parent's expectations and joy at the prospect of the new life change into despair and grief; accompanied by lost dreams of a positively changed future. Immediately, the woman or couple find themselves in the throes of loss, which can be a life-altering experience. This event has been shown to be different from other types of losses, the magnitude of which may endure permanently, as we shall appreciate in our final story.[1] The psychosocial impact of perinatal death has been studied for over twenty-five years. The informed attitude expressed in our care can assist the grieving families as they move along the difficult path through loss into grief and

healing.[4]

Professional and societal attitudes have changed markedly since the 1970s. Women were not content with being 'parts' in an impersonal process. The awakening and articulation of women's control of their bodies and the demand for participation in one of the most emotionally important experiences of their lives, changed the participation level of women and men. The psychosocial management change of still-birth trauma was championed by parents and doctors starting in the late 1970s.[10,12] The previous attitude was to put the loss behind you and look to the future. A medical impetus for change began in the 1970s with papers by Kennell et al ["The mourning response of parents to the death of a newborn infant." New Engl J Med 1970; 283:344-349, and by Lewis in the UK] This was a change in which clinicians recognized the severity of parents' loss, and for sensitivity in the (medical) response, accompanied by a more open attitude toward dying and bereavement and other personal crises.[5]

There is an obvious increased attention to the psychological and spiritual effects of pregnancy loss on women and their family - from spontaneous abortion to neonatal death.[5] It is now recognized that the trauma of stillbirth can have long-term effects on the family as well as the mother.[23,30] Depending on factors which will be mentioned below, up to a fifth of women (and men) have prolonged depression or morbid preoccupation thoughts of the dead baby, misdirected anger;[31] and a fifth suffer PTSD (post-traumatic stress disorder) in a following pregnancy. I have certainly noticed increased obsessive-compulsive disorder, and marital discord and even suicide can supervene.[24] If the anxiety or mourning is unresolved, there could be a disturbance effect on the next born child,[12]and certainly parents have been found to have elevated levels of anxiety during the subsequent pregnancy.[24]

Twenty to thirty years ago the standard was to regard a stillbirth as a 'non-event'. Parents were discouraged (prevented) from meeting the dead baby, the hospital policy concentrating on protecting the parents from grief (and of course the husband was not to be present for a stillbirth): "After rapid ligation and severance of the cord, the infant was removed from the room and the parents never were able to see their child."[18] (Later or in the question period we may be introduced to the current controversy of encouraging the holding of the child.). While today perinatal death is no longer a 'non-event', the public disclosure and open support is still taboo in society, and, to make matters worse, the parenting ones are still discouraged from talking about the actuality of their loss and of their deep sadness.[7]

Each loss is unique, requiring a tailored empathy, assessment and evidence-based intervention/ response - from wherever in the continuum the professional encounters the tragedy - thus "health care providers should avoid a 'cookbook' approach to perinatal loss."[24] More often than not, the loss impacts young people/ families who have limited experience with any type of loss. In spite of studies, grief accompanying perinatal loss is still little understood in our practices. We, health care professions, are faced with the clinical challenge of how to care for and help parents cope with perinatal loss of any type.[4] The process of providing holistic and spiritual care for a family should not begin well after the fact, but as soon as there are any indicators of danger to the woman or unborn child.

2. DEFINITIONS AND STATS

a) Medical markers

I am not a medical practitioner nor a medical statistician, but one is aware of differences of conceptual definitions and numerical markers. The point of mentioning distinctions and markers is that there is no finesse of language for the mothers and families in the loss and grieving column. Perinatal loss includes early and late fetal death (or, miscarriage and stillbirth), and is sometimes extended to include neonatal death (the death of a child in the first 28 days after birth). Perinatal death in North America affects millions of families each year. Cramer and Wise (2000) reported that 12% to 31% of all conceptions end spontaneously in an early or late fetal death. In addition, the (U.S.) rate of miscarriage (unplanned, unexpected loss before 20 weeks gestation) is estimated at 16%.[24] Late fetal loss (or stillbirth)occurs in approximately 1 in every 150 pregnancies (2003 stats) and neonatal death occurs at a rate of 6.8/1000 live births. The most recent U.S. statistics (2003) show the rate of combined perinatal loss (stillbirth and neonatal death) was 11/1000 live births (National Centre for Health Statistics, 2003). [24] Using slightly different markers in the UK, it is 8.1/1000 perinatal loss (stillbirth after 24 weeks gestation and neonatal death in the first 7 days).[10] Put against the backdrop of (e.g. UK) stillbirths at 28/1000 in 1948, technical advances have been effective (at the same time, sensitivities increased with the movement to reduce medical paternalism).[12] According to StatsCan (2003), in 2001 2,042 babies were stillborn (after 20 weeks of gestation).[7] Regarding miscarriages, the estimate (Canadian) is 15% of clinically recognized pregnancies (or estimated as many as one third of all pregnancies), with the prevalence of miscarriage increasing with maternal age (from 12% in women younger than 20 to greater than 50% in women older than 45 years). Sometimes she “knows” before it is “discovered.” One study in Sweden reported that 23% had a ‘very strong’ feeling that the child could be dead.[2]

While there are legal (and perhaps medical) ramifications between gestations of less than 20 weeks (miscarriage) and post 20 (stillbirth), the gestation period does not determine the meaning of the baby and the event to the mother and family,[7]nor to their social and relationship networks[27]. The attitude of the healthcare professional is important. If the professional does not see the baby as baby, whatever the gestational age, the impact will be different from the care provider who sees the child as a cherished baby: “Language cocreates human experience.”[7]

b) Spirituality

There are scores, perhaps hundreds of definitions of spirituality. Spirituality is not only prominent in health care, but also in the work place. In contemporary history, most of you know that it stands at the centre of the AA program. At our own Cancer Treatment Centre, we have a brochure which lays out our understanding. It may or may not fit in with your usage of the word.

Spirituality is an integral component of healing. It is a source of strength in the presence of distress. It is at the heart of our well-being. It enriches all aspects of our life: physical, mental, emotional and community.

Spirituality is a life force that promotes hope, encourages healing, helps us to embrace ourselves

and others. Spirituality is expressed in the attitudes, beliefs, and practices that influence people's lives. Spirituality enables us to experience the transcendent or higher power. Spirituality involves family and friends. It embraces fullness, meaning, love and hope in the journey.

What are Spiritual Needs?: MEANING - Who am I? Why is this happening? PURPOSE - When do I feel most alive? COMMUNICATION - With whom and how can I be open and honest? BELONGING - Who cares for me? HOPE - Where does my hope lie? VALUES - What are my guiding principles? CREATIVITY - Do I feel free to shape my own path? RELATIONSHIPS - How do I see myself now in relationship to myself and others? FORGIVENESS - Am I forgiving and forgiven?

In the cancer setting, we ask about symptoms of Spiritual Distress, but perhaps these markers can be applied equally to fetal demise? * fear * pain * anxiety * confusion *depression * anger * hopelessness *loss * apathy * shame * guilt * grief * withdrawal * isolation *resentment * disbelief * conflict * regret * loneliness *powerlessness [41]

Attendance to spiritual care has beneficial effects according to evidence based research. Spiritual well-being and meaning serve as a buffer zone against depression and hopelessness. How do we all best offer spiritual care? As we enter the world of the patient and family it gives them an opportunity to reflect on what is happening to them and how they feel about the sadness and challenges they face. I found the following in the U.K. in a booklet on spiritual aspects of nursing care, but it applies to all of us:
• a willingness to leave our preoccupations aside.
• giving focused time and attention, even for a short while.
• being sensitive to whether the person wants to make use of us; maybe for them it's not the right time or we're not the right person.
• helping to create the space for people to connect with their own reality.
• non-judgmental listening, in which our own 'stuff' does not get in the way.
• active listening, in which our concern is on what is being said or not being said rather than how we can respond.
• 'staying with' strong feelings rather than trying to close them down.
• 'staying with' the hard questions rather than resorting to easy answers.

Spiritual care cannot be boxed in nor narrowly defined. Spiritual care is provided not only for those who believe in a certain way. Spiritual care is for everyone. Spiritual care includes whatever gives a person meaning, worth and value. People may express their spirituality in unique ways, but everyone has a spiritual nature that can be touched through the ministrations of another. (This insight reaches back several years and is adapted from the Preface of Spiritual Dimensions of Nursing Practice, ed. by Verna Benner Carson. W.B. Saunders Co. USA, 1989) Spiritual care involves other mediums, such as the healing power of music, tai chi, yoga, painting and therapeutic touch.

Joni Walton, writing in the Nephrology Nursing Journal, observes that "insight into the spiritual realm of patient care will transform nursing in this millennium. Harnessing the restorative powers of spirituality and caring for the body-mind-spirit of nurses and patients alike are kindling a spirit of renewal within the nursing profession." [43]

The importance of spirituality as a central component of well-being is increasingly recognized by

doctors and mental-health professionals. Spiritual well-being is important.[44] Many health care professionals are now paying attention to the importance of spiritual health. Growing data have provided empirical support for the hypothesis that spiritual well-being and health are positively correlated, and that consumers of healthcare are increasingly using "spiritual healing" and religious resources to improve health. This is also seen in all models of "well-being". [45]

Spirituality stands central in the application of nursing principles. Regardless of whether people experience spiritual stress or not, spiritual needs are an inherent part of living.[46] Principles of spirituality practice could stand at the centre of dealing with fetal demise.

c) Spirituality in Med Schools

We do know that the hesitancy of entering into the spiritual realm of patients is shown by a high percentage of physicians. It may be exacerbated with insensitive words, body language and cultural hesitancies. This has serious ramifications for the promotion of well-being. However, there is a change in medical education in this field, paralleling a greater understanding in society. In the U.S., there is a marked increase in med schools teaching courses on Spirituality and Health. Out of 141 medical schools in the USA in 1992, there were three schools with spirituality courses. By 2004, 102 of those schools had at least one course, 58 offered more than 1 course; 43% are integrated and 70% are required.

Examples of topics in spirituality and health include: Spirituality in different clinical situations - childbirth, chronic illness, grief, surgery, life stress, end of life; spiritual history – how to communicate about spiritual issues; ethical guidelines; suffering; spiritual care models; religious, cultural and spiritual values and their impact on healthcare decision-making; role of ritual, prayer, meditation, cultural customs in healthcare; role of multidisciplinary team in spiritual care; role of spiritual and religious communities; ways different religions and cultures view ethical issues in healthcare; spirituality of the healthcare professional.

The interplay between the medical and spiritual specialists would seem to be on a path of greater cooperation. The National Comprehensive Cancer Network (an alliance of nineteen of the world's leading cancer centres) lists several indications for referral to a spiritual care specialist: - Grief; Concerns about death/afterlife; Conflicted or challenged belief system; Loss of faith; Concerns with meaning/ purpose of life; Concerns about relationship with deity; Isolation from religious community; Guilt; Hopelessness; Conflict between beliefs and recommended Rx; Ritual needs. Several of these themes are those found in the stress of fetal demise.

3. LANGUAGE, AND THINGS (NOT) TO SAY

Many years ago during one of the early training sessions in clinical pastoral education, I was assigned to a teaching hospital for a three month internship. An asthmatic young man from the rural area was accustomed to checking himself into the hospital during an impending serious attack. I was there early one morning when his elderly parents came in to the front desk and asked if their son ____ had checked in... and the clerk said, "Oh yes, ... he's expired." To which his father replied, "Yes, he often has

trouble with his breathing, could you tell me what floor he's on?" The impact of that has stayed, and is a constant reminder of using plain language wherever possible. Even so, you can imagine our surprise when one patient at our cancer treatment centre interpreted our multidisciplinary office (and sign) to be the place where various forms of discipline were exercised for non-compliant patients!

Unfortunately, parents report being subjected to hurtful or unwanted comments from health care professionals, and not just the docs - such as the following which have been told to young parents: "You were only pregnant for 3 months, it wasn't even a baby yet," "You can always have another baby," "Be sorry for the parents who have lost a child in a car accident or to leukemia," or "there probably was something wrong with the baby; it wouldn't have been 'right.' You're better off losing the baby now than later."[4] Not only are comments such as these hurtful at the time, but can erode trust and inhibit a healing process.

Here are a few other words that are:

Not helpful/ potentially harmful	Helpful
You can have another one	I don't know what to say.
It was for the best, he might have had brain damage	I am sorry.
This part of your life is over. You need to move on	I can't imagine what this must be like for you.
Lucky you have other children at home	I am so sorry for your loss.
At least you didn't know him/her	Did you name your baby? What is his/her name?
God needs angel babies too	What is this like for you?
Time heals all wounds	How will you get through this? What will help you now?
{Or, to re-examine the title of today's talk}	
Dealing with fetal demise	This fetus is the baby of our hopes and dreams.

Whether we like it or not, words used by all health caregivers will linger with families who are living with loss and eventually with the memory of loss. Many mothers and fathers whose babies did not can recall the circumstances of what happened and every word said or not said to them. Of course, healthcare providers would intend to do no harm, but harm does happen because of language used with parents. Even well meaning language intended to comfort and to ease the pain by trying to diminish the loss and hence the suffering doesn't work. "....Terms such as 'resolution of grief' should be avoided. Many parents do not want to forget their dead babies, feel grief is a lifelong process, and resist the notion that they will someday feel as though the loss never happened." [24] When the meaning of the loss is significant, as it is, wrong language can be more hurtful and even potentially harmful. Staff who use technical terms and leave the room without giving an explanation give rise to reports of frustration and negative feelings.[7, 18] Careful empathetic language and fully acknowledging the loss can enhance the quality and meaning of care during this crisis.

It is far too easy to slip into platitudes or medical routines. The existential pain cannot be cured in medical terms. Rather than 'telling', parents could be more helpfully 'asked' about their feelings - especially if one suspects self- or other-directed blame or anger. Religious 'injections' are likewise ill-advised. Failure to understand and stay with strong feelings may hinder the opportunity for a therapeutic response.

Clergy, social workers, doctors, technicians and nurses all have different thresholds when relating to death. Fear of death in our psyche will distance us from the pain and shock that a little one has died. The effect - from words to silence to body language - will impact the family. Whatever the healthcare professional may believe personally about the fetus - as issue, baby, infant - during early loss especially, the professional stance is that it is about the woman and parents. In early loss, we cannot assume what the meaning is, either way. It has been reported in one citation that 70% of women experiencing a miscarriage or early loss believed their babies, were babies (Allen & Marks, 1993). Put bluntly, *our* views do not take precedence over the meaning held by the mother and family.

Appropriate language can enhance the quality of direct and supportive care when a mother or couple suffer the loss of a baby prior to birth. The theme is that *language used in times of crisis is extremely important, as it has the potential to either intensify suffering or enable the woman and family to move into an appropriate grieving and healing.*

4. ULTRASOUND

"It was like a curtain had been pulled down; it was trying. I didn't believe it was true, it simply couldn't be true. At the same time, I saw on the ultrasound screen that the baby was not moving. In fact, I don't know how I felt ... shock, it's impossible to describe it. I don't know what could happen that could be worse."[17] (a father's reaction)

Nearly 40% of the women in one study reported that they were either sad, deeply hurt or angry about the behaviour of one or more members of the medical staff ... listen to the following: "When the physician diagnosed our baby's death with ultrasound, she was very insensitive. She just said, 'Yes, it's dead!' Then she brought forward a medical intern to show how 'slack' the child was."[2]

The sonographer is in such a difficult situation. And so is the woman. The nightmare can begin so subtly and turn quickly. Another woman: "I made the mistake of asking her if everything looked okay, and she didn't answer. She said, well, there are a few things I want the doctor to look at. So at this point I become almost hysterical because something's wrong and she knows it."[34]

Many ultrasound technicians will relate to the atmosphere change in the ultrasound room as any first signs of a problem appear. For the woman, it is the first signal that something is wrong: "Each respondent felt as though the ultrasonographer just stopped talking to her, and from that point on, she suspected that there was a problem with the fetus. 'The sonographer was chat chat chat: then she just stopped talking to me. And I thought, okay this is bad. I could never have envisioned how bad it was.'" [34] As more and more partners attend the ultrasound session, this charges the room even more, and as we shall discuss below, men who attend the ultrasound scan have the same or similar affective feelings as their

partner.[33] Since a conspiracy of silence leads to fear and apprehension, it has been suggested that mother be kept informed, in non-medicotechnical terms, throughout the whole process.[6, 18]

Most women probably regard the practice (of one or two scans per pregnancy) as a pleasant opportunity of 'meeting their baby' and increasing the 'bonding' rather than as a medical diagnostic test. Seeing the fetus during an ultrasound examination increases the bonding process by making the 'little one' seem even more real to the mother and family. [The Tom Cruise syndrome?] They anticipate ultrasound as a positive or enjoyable opportunity to greet their baby and get a picture of their baby... and then they e-mail the picture to their friends (not suspecting the pain it might bring to a friend who may have just had a miscarriage). If we are concerned about loss counselling, then this is related to potential risk knowledge. It seems that there may be little preparation for anything other than a picture of a normally developing fetus. A Canadian study (with similar results from elsewhere) of 49 women in Montreal undergoing their first routine ultrasound indicated that none reported being asked if they wanted one, and none recalled being told what ultrasound could or could not detect.[35] Is the standard of informed consent always applied? One would hope so.

In spite of the widespread and decades long use of ultrasound technology as a critical diagnostic instrument for prenatal care, relatively little research has been directed to dealing with reactions caused by unexpected negative findings. L.M. Mitchell (2004) suggests that "... the manner of presenting abnormal findings to women, women's ability to see the impairment on screen, and the impact of dashed expectations for a happy 'baby's first picture' have not been systematically studied." [35] Also, in the discovery of anomalies, women report that they had not thought of ultrasound in that regard too. Similar to the earlier examples, one woman commented, in other research: "We were so naive. We thought we were going to see the baby and get a nice photo. I had the ultrasound. I did the tests. I couldn't believe it (fetal demise) had happened. Grandma wanted to come... and the kids wanted to come, so they came with us... So everybody's up, you know ...like, 'Oh, let's go see the ultrasound. Let's go see the baby." [35] The assumed bright world suddenly becomes a blur.

It is the doctor's responsibility to give disclosure. This may be the most significant moment in the parents' bereavement process.[1] A radiologist's or other physician's sensitive approach can make all the positive difference in difficult times.[1,17] Yet there can be gaps for those who leave the ultrasound room without any major indicators told: "We went for the 20-week scan. It was all laugh, laugh, smile, smile, and then nothing. The technician said, 'There's a problem; you need to get hold of your doctor as soon as possible.' Well, that was Friday afternoon. So we waited all weekend in a complete panic. First thing Monday morning, I called the doctor. She tells me, over the phone for god's sake, 'Your baby won't survive.'"[35]

Sometimes, early pregnancy loss is discovered during an ultrasound. It is important that the woman be informed of the loss clearly at the time of the scan. The physician conducting the ultrasound should tell the woman of the findings and contact her physician as soon as possible, so that ongoing care and support can be coordinated. Providing immediate emotional support is critical and may ease a woman and her partner's natural reaction to the loss. It is crucial, too, to express sympathy, provide an opportunity to ask questions, and offer a quiet place for initial reflection. It may also be important to reassure the woman that she is not to blame for the miscarriage. The parents should not be left alone; that is, not sent home alone or sent to the hospital to check in alone. A relative, friend, neighbor, support

person, or hospital volunteer should be asked to accompany the parents. Most women and partners say they need information about the cause of the loss and about any further care required. In general, the woman's own physician, rather than the ultrasonographic physician, is better placed to provide the detailed information required. [36, pp 13-14 (Public Health Agency of Canada publication)]

Different policies and protocols at various hospitals/ clinics influence the direction of the outcomes. But, the skills to discuss the findings openly with the mother (and those present) are indeed critical. How to deal with the profound bewilderment, the sadness and disappointment? Certainly any anger against the staff and doctors needn't be challenged now. Just understanding. The outpouring of emotions should be allowed to flow, without blocking or platitude. Just understanding. In a perfect world a skilled physician will be present to absorb the flow of questions after the immediate shock of hearing of the fetal death (or severe anomalies).[6]

5. SKILL-SETS

"Health care providers have the opportunity to play an important role in the healing of bereaved parents with their support, understanding and warmth during the time surrounding the loss of the baby." [1]

How do you/we respond? Probably pretty well. Standard care practice usually includes a support system and empathetic milieu which assists the mother and family in accepting a perinatal death. But the experience of those who have not received a healing response suggests that silence and avoidance greets them far too often. The skills of empathy, communication and honesty go a long way. And so does presence. 'Don't disappear,' may be the woman's silent cry.

Attention to the partner requires even extra sensitivity, for it is known that men who attend the ultrasound can have the same reactions as the mother in terms of bonding with or knowing the baby. [33] The impact of loss on fathers who have seen their babies on ultrasound is greater than on those who had not seen.[3, Armstrong, 2001] {Expand or footnote}

As mentioned, it is the physician's responsibility to give disclosure. Not an easy obligation for anyone. Physicians' management of parents' grieving is critically important. We know that it is important to speak with both parents or one parent with another support person. Simple language, time for listening and the honest answering of tough questions is paramount. Many women (and partners) will have a serious grief reaction which often passes unacknowledged or recognized, and can extend into the next pregnancy. It can lead to acute psychosocial /spiritual distress. The grief counselling remains an area in which obstetricians, radiologists and ER docs receive precious little training,[6] "...it has been stated that they lack well-grounded knowledge of bereavement counselling."[26] The professional health care team approach acknowledges the sensitivity of all members in building a structure for the recognition and care of spiritual and psychosocial stress. The clinical policies and procedures for the care of the patient going through perinatal loss would also reflect the right of patients and families to be included in any decisions concerning their own care and that of their baby.[Midland,14] The key is to build a relationship, with the usual high standards of providing supportive care - being present, taking time to address their questions, listening to and accepting their emotional expressions without trying to be a fixer or defender (a simple 'I'm sorry' can be the best comment), while being sensitive to parents' unique emotional, spiritual and

religious needs. The patients need to trust those who will help them navigate the uncharted waters. [Davis,14] Rituals become important, and one intervention appreciated by parents was being informed of the "...value and importance of rituals in coping with their grief."[27] Since the pain is frequently existential or related to the meaning of the event, a clinically trained spiritual care person should be part of the interdisciplinary team. As part of team skill-set building, it has been shown that health care professionals' perceptions of the emotional (and one would assume psychosocial /spiritual) needs were significantly increased after attending an educational program.[4]

6. LOSS

Loss, in any form, impacts on behaviour. One of the most pronounced and least understood types of loss surrounds fetal death: "perinatal loss has been associated with depression, anxiety, obsessive-compulsive disorder, suicide, marital conflict, and post-traumatic stress disorder."[24]. Perinatal loss includes most negative pregnancy situations, including miscarriage, stillbirth, therapeutic abortion, and even neonatal death. Even though this type of loss occurs in up to one in five women, the women and their families "suffer in silence and isolation" because friends, other family members and health care professionals often provide inadequate understanding or support. [4, 49] Perinatal loss and grief is very complex and different from other forms of loss. [29] The emotional effects of the loss are not fully understood.

Perinatal loss is often 'invisible' to the rest of society. Parents often experience an isolation which adds to their sense of loss, especially in a mobile society like Canada where many young people do not have an available mother figure or close support. Some data suggest that the mother's and father's response to the loss appears to have become more pronounced as the perinatal death rate has fallen.[6,50] Parents, denied grief/mourning time, can become frustrated, especially when asked why they are not over it yet.[32] For the parents, the loss is not only for the child *per se*, but represents the loss of the baby's anticipated future, their own dreams and their anticipated parenthood, a loss of self accompanied by a sense of biological failure.[1, 29] Self-blame (and self-criticism) following a loss is a salient factor in a woman's inability to cope, and is difficult to resolve within the context of bereavement.[22]

In loss, the level of attachment will contribute to the sense of the depth of loss, although each loss will be unique for the person. Initially, support providers will get to understand the significance and meaning of the loss as related to the 'reality' of the pregnancy and baby to the parents.[24] The felt intensity of the loss has usually been related to the gestation age in early research, but while generally true as a significant predictor, the pre and post 20 week marker is not absolute, as the level of attachment has several variables in addition to gestational age (number of living children, previous losses, age of mother and so on), [22] with the most important being the degree of bonding or attachment developed with the baby up to its death[1, see ft 6] . The "wantedness" of the pregnancy is a determinant of the felt loss, not the gestational age. [34] For some parents that attachment occurs very early in the pregnancy, and a miscarriage can be devastating. Once the attachment level reaches the point of naming, or using pet names, the linking of a specific personality to their baby, the loss consequences can be intense and will last months to years, [24] especially in the absence of an appropriate grieving process. It is important that caregivers are acquainted with the loss history of pregnant women in order to be even more supportive, for research indicates that women with a history of reproductive loss showed more symptoms of depression

and anxiety during their pregnancy.[23]

An increasing phenomenon is multiple gestations, brought about with the increasing use of assisted reproductive technology, and fetal loss occurs more often in these situations. Having a still-birth and a live birth at the same time is a complex situation in that two conflicting psychological processes occur.[1] It is almost not possible to celebrate the life of one (in the case of twins) and at the same time grieve the death of the other. It has been noted that parents may even blame the surviving twin for the death of the other, and child abuse is reported to be common.[6] Bereavement counselling needs to be sensitive to such issues, or mourning might be postponed or give rise to symptoms of failed grieving. The surviving child is "also at risk of psychological sequelae and may later develop the burden of survivor guilt and identity confusion."[6] If possible, photographs of both the live and dead fetus, together and separate, should be kept for the parents.

Ripples of loss spread to others in the family group. Expectant grandparents find this very painful and don't know how to answer the questions. There is concern for any siblings. It might be noted that the loss of a brother or sister during the perinatal period may affect the siblings much more than parents assume: "Children may have feelings of guilt or fear and may have difficulty in resolving their anxiety by themselves."[1, 37] Older children may have unresolved loss issues, and parents may be so preoccupied with their own grieving that their children's emotional needs are overlooked.[10] Longitudinal studies suggest that the next born child after a perinatal loss may be subject to 'vulnerable child syndrome', being treated with particular anxiety. [10]

Additionally, loss experienced by adolescent parents is often minimized by family, society, peers and school ('she can replace the lost baby with another, can enter back into mainstream adolescent activities'), and these adult-children who have less experience with loss and life circumstances are at risk at isolating themselves from their parents, and are also at risk for complicated unresolved grief.[1]

There is general consensus in the literature on the impact of perinatal loss, but the findings surrounding the variables predicting grief outcomes are far less clear.[5] [23]

7. GRIEF

Grief management is the goal of a wide-based health care response to perinatal loss, with a myriad of participants trained to provide responsible care to the grieving family - diagnostic imaging personnel, the spiritual care provider, social workers, chaplains, mid-wives, physicians, clergy, nurses, ER staff. The goal in the first stages of grief management is to help the family experience a healing grief reaction, to name the loss, to assure the family of being able to express what often turn out to be normal feelings and to meet the needs of each unique family.[1] After perinatal loss, parents invariably go through a period of grief. Mood depression, anxiety, sadness, sleeping and eating irregularities and preoccupation with the lost baby are part of the normal reaction to severe loss.

Grief has different expressions, and parents need to know that the grief experience is unique to each person experiencing it. Once the emotional numbness and bewilderment subsides (which may last from a few hours to a few days), parents need assurance and guidance about the grieving process, as well as

ways to protect themselves from hurtful albeit well-meaning advice and comments from friends, family members and even health care workers.[16] Partners in a couple may have totally different perspectives and may grieve incongruently [24,29]. Social networks are affected. It is common that there will be a permanent rupture of some relationships with friends and relatives and co-workers.

While the time line is never absolute, the process of direct mourning a perinatal loss typically takes up to one to two years,[24,10] although most should expect to show a mood improvement by six months from loss [10] Perinatal grief can last longer or it may never be complete. (The Perinatal Grief Scale (1989) was constructed to incorporate the various dimensions of grief and continues to be used in studies of pregnancy loss.[5]) However, the intensity and duration of grief is frequently longer than anticipated. Many think parental grieving is a life long process. The intensity will usually lessen with time.[29] Spikes in the process may occur in milestone or trigger events - such as anniversaries of the baby's death and expected due date; Mother's and Father's Days; family holidays. [24] Interestingly, I find grief reactions in various forms of loss at the nine month level. The loss is never 'resolved' but *grief adaptation* is described by some authors as when a family finds ways to live with the loss, but never forgets it.

"Normal" grief is an elastic concept, and when it flows into complicated or pathological grief is difficult to define. There are few research accepted markers of normal/ uncomplicated versus abnormal/ complicated grief.[29] Clinical opinion may be summarized as pathological grief being differentiated from normal grief by its duration and the degree to which day to day behaviour and emotional states are affected.[10] Indicators of complicated grief for health care workers and family would include lack of expression of grief, substance abuse, suicidal ideation, acute depression, daily living activity blockages. Associated factors might include poor social supports including from a partner, pre-loss neurosis, mental health history. These flags would assist the medical and support staff in assessing the need for a mental health care provider. Even in a 'normal' process, if the grief symptoms continue without any abatement for more than six months, a psychological assessment or referral is warranted.

Grief after perinatal loss falls within generally accepted theories about working through grief,[21] even though there is a uniqueness and complexity about perinatal loss. While many medical 'structures' build grief counselling into their service protocols, the initial response of health care professionals caring for mothers and families who are experiencing the loss of a baby is critical. All staff - from sonography to obstetrics - should be familiar with the process of grief reactions so that they can offer optimal support during this initial and important stage. While the natural inclination of medical carers is to shield the grieving parents from decision making, an important aspect of initial grief care is to offer involvement and participation choice: "by enabling the woman, whenever it is clinically sensible, to make decisions appropriate for her and her family, the process of bereavement is more likely to result in a successful resolution of the emotional disorder which accompanies perinatal death."[6] The grief bereavement trained social worker and/or spiritual care provider should be apprised of any significant needs of the mother and family in these initial stages.

Grief counselling should be available to all. Even in healthy grief counselling, it is not uncommon for parents to be engaged in the healing process for a considerable period. For example, I use a Grief Recovery Handbook [42] not before at least six months following perinatal loss. Each practitioner will have their particular methodology, but what is underlined here is the empathetic support the health care providers can professionally and sensitively offer at the time of discovery - as frequently happens during

ultrasound.

8.. INFLUENCE OF CULTURE AND RELIGION

Spiritual care should be made available as soon as possible, with all parties respecting the parents' cultural and/or religious background. This can be important even as early as autopsy considerations.[1] Sensitive evaluation and follow up for potential counselling as a result of pathological grievances will be required. The cultural-religious distinctions and their impact on psychological grief adjustments to perinatal death is an interesting area for awareness, but it is not systematically studied yet.[31] The hospital spiritual care provider or hospital chaplain, or the family's own religious advisor (minister, priest, rabbi, etc) can be of help in talking about rites such as funeral planning, grieving norms, cremation, burial and so on. Once again, the priority is on responsible listening from the staff. One of the best questions a staff person can ask may be a simple "...how can I help you honour your family traditions at this time?"[32]

The role of the cultural/religious model allows the emphasis of the meaning of ritual which is designed to mark and dignify the loss of a child. Even while there are similar patterns which the spiritual care department should know about, there is not a sameness between all groups, nor between all adherents of a religious or cultural persuasion. For example, for most Christians either cremation or burial is acceptable, but an exception would be the Latter Day Saints, who believe in physical resurrection of the body and therefore do not permit cremation. Even baptism, which most nurses are prepared to administer in the absence of clergy, requires prior consent from parents as some Christian parents of stillborn infants see them as being without sin and not in need of this sacrament. (A simple blessing and naming ceremony may be a good alternative)

A recent article by Melanie Chichester [32] summarizes several religious cultural reflections and is quite helpful. In certain cultures, such as the Hispanic community, the extended family may be very vocal and emotional when hearing that a baby has died, reflecting the deep value children have. Showing respect and *personalismo* or friendliness to the family spokesperson helps in the communication.[40] (A DI specialist friend and I were discussing the numbers who wish to be involved in the ultrasound procedure in the tropics where he practiced, he decided at one point that only the mother would be present because so many people were crowding into the practice. Now, if everything is o.k. the father will be informed!)

In Judaism, general viewing of the body is often considered disrespectful; orthodox and conservative Jews may decline seeing the baby or taking pictures of the dead fetus.... but since pictures of the living are acceptable, an ultrasound image of may be particularly importance to the Jewish parent. Autopsy is generally forbidden as it desecrates the body, but since preserving life is more important and if the results of an autopsy could help save another's life, then it might be permissible. The body of a stillborn is wrapped in a plain white shroud and buried (preferably within 24 hours). Cremation is forbidden. Again, the loss of a child is regarded as a family tragedy, and care of the stillborn is based on kavod ha-met, treating the dead with respect, and to ensure the respect, a family member may wish to be with the body at all times. Gestation determines funeral and mourning practices in that before four months (or quickening), mourning rituals are generally not used.

"For Muslims, death is considered part of life, and life is seen as preparation for the afterlife with Allah."[32] Since an infant who dies is seen as sinless, the child returns directly to Allah. It is important to relay information to both parents, as decision making is shared, and most decisions will be made overtly by the father in many Muslim cultures. Modesty is valued, so the woman will appreciate only females caregivers as well as efforts to keep her body covered at all times.[39] Like Jews, and for the same reason, autopsy is usually forbidden unless there is a pressing reason. The dead are not to be viewed unnecessarily, so the parents may not wish to see the baby and may request that others not see the baby. Pictures are not usually taken of the dead, but the parents may do so without censure. Taking locks of hair is not permitted as the child's body is to be buried intact. Also, Muslims are buried not cremated, preferably within twenty-four hours. Again, for babies less than four months gestation, the fetus will be wrapped and buried. After four months, the fetus is named, washed, wrapped and buried, with the option of janazah, (funeral) which women do not attend.[32, 38].

In Japanese culture, pregnancy loss is a lifelong parenting and grieving experience, which finds expression in statues and offerings to Jizo, a powerful enlightened being who watches over children. In Japanese the word for miscarriage or abortion is *mizuko*, which loosely translates as 'water child,' or liquid life, somewhere between life and death. Japanese Buddhists believe that existence occurs over time, and children are not considered to be complete until they reach the age of seven. Prayers are offered for children who are stillborn, miscarried or aborted, with the expectation that Jizo will help all mizuko babies "... find another pathway into being."[14,Rybarik]

Staff, nurses, doctors, spiritual care workers can all mindfully respect the beliefs and customs of others, even when we do not fully understand or appreciates the beliefs and customs of those who are different from those we might embrace. The hospital spiritual/ pastoral care centre is a key resource to help provide culturally sensitive care for different faith traditions.[32]

9. SPIRITUAL CARE AND COUNSELLING

Spiritual support should be made available and the parents' cultural values respected.[1] Nurses have had spiritual care material available to them for a long time. As mentioned above, medical schools are more and more including spirituality in their curricula. Certain areas of medical support such as the Canadian Association of Occupational Therapists have put Spirituality at the centre of their constitution.

Spiritual care is found through hospital spiritual or pastoral care offices. Also through Chaplains' offices. Hospital based spiritual /pastoral care providers are highly trained in clinical pastoral education and/or pastoral psychology, with expertise not only to deal with grief and trauma, but also to lead and participate in team approaches to various critical situations faced by hospital departments. Unfortunately, many colleagues in the hospital setting think of them as "religious doers" to be called in after the fact and at the request of the patient. Asking a patient if they would care to speak with a spiritual care specialist is akin to asking a patient with a multiple fracture if they would care to speak with an orthopaedic surgeon. But don't get too excited about involving the spiritual/ pastoral care department for each instance, for most are stretched beyond recognition already and are underfunded. Social workers are also trained for these situations, and should also be called.

Involvement with the spiritual care provider "... to discuss the spiritual concerns so intimately related to the death of offspring for many families" is very important:[20] "But of course there was quite a lot to talk about. And the female hospital chaplain, in particular, was invaluable even much later and still is. At the same time, the midwives we came into contact with were extremely good; they piloted us along, taking one step at a time, It felt that way even then, but perhaps I have come to realize more and more afterwards just how well planned it was."[18] Skill at creative listening is important as the mother and family experience the feelings of sadness, denial, guilt and anger in facing the loss and as the healing process of grief begins.[8] Pregnancy loss at any point may raise deep issues of meaning - 'how can I understand or make sense of what seems so unjust?' - which is a spiritual/ pastoral care question. Members of staff can contact the spiritual/ pastoral care department at any time. Also, the department will contact a religious representative of the family's choice or inclination. Spiritual/pastoral care services also include mourning opportunities for pregnancy loss, rites for healing, memorial and burial services as required. Support can come in various ways, from in-depth counselling in loss, to supplying a book of remembrance or a ritual when parents leave for home to allowing the parents to realize they are not alone in their anguish. Here is but one example: "The nurse next called the hospital chaplain. The chaplain arrived in L&D about ninety minutes after the couple, giving them time to be admitted and to settle into their new surroundings. The chaplain led an in-house support team for couple experiencing a stillbirth. Volunteer visitors (trained, with personal experiences of stillbirths were available to assist the chaplains when appropriate. The volunteers were on call when the [chaplain] was not available, assisted the nurses in gathering mementoes, and made support visits with the couple."[17]

Timely professional support after the discovery of perinatal loss comes through the wide potential base of health care providers, whose role is different from those supplying social support (partner, family, friends, networks). Counselling can include other interventions such as teaching, encouragement, problem solving and role modeling. This professional support may lead to improved health outcomes. [24] One particular intervention, beginning in the ultrasound period, is to decrease any self-critical or blaming attitudes a woman may have. These may mean providing reassurance that she was not responsible for the loss, keeping all informed questions answered. If the woman seems to be overly self-critical, this is the time for referral in order to generate counselling therapy targeting self-critical attitudes.[22] Sometimes the intervention will be as "simple" as giving guidance about explaining the death of the baby to their other children. Counselling may involve the couple not only since it is a joint loss, but for marriage counselling since marital conflicts commonly occur during the first twelve months from the time of fetal loss.

Nurses' physical and spiritual care to a family after pregnancy loss can set the framework and support for a woman's entire grieving-healing process. The nature of nurses' and staff compassionate care exceeding the patient's expectations while being based on well-grounded theory and research, is essential. A medical community can respond to the physical needs with the utmost competency. The difficulty is in response to psychological sequelae,[16] and any related spiritual support: "the most beneficial commodity any nurse can offer to a grieving family is a nonjudgmental, deep sense of caring and personal involvement. Whether or not nurses have received specialized training in bereavement, their role requires that they provide compassionate, appropriate care for all patients."[16] At this time that care-giver can perhaps spot any potential need for counselling services - from the spiritual care clinician, social worker, psychologist or support team.

10. STANDARD OF CARE

Standards of care for fetal demise involve procedures, assessment, intervention, education and follow-up. Since the news received by the parents could well likely be a first experience with death, we need to realize how much they rely on the health care team for support, knowledge and direction.[32] Caregivers, from sonographers to pastoral care workers, can assist the newly grieved mother and family to have positive memories of their baby by giving them a real feeling of being cared for in the midst of their pain and grief: "Experience has taught us that when bereaved parents feel that healthcare personnel are sensitive to their situation, provide anticipatory guidance, and present opportunities for positive memories during the brief time they have with their baby, they are better prepared for the difficult journey of grief."[Midland, 14] Since staff are also shocked and upset when there is a demise, it is appropriate to have a protocol in place, especially for inexperienced staff who might be uneasy with what to say or do when, for example, the baby is found to be still. But these would only be guidelines, used to reduce staff anxiety as much as the patient's. [12] While protocols and guidelines are necessary, it cannot be reiterated often enough that each case is unique, although with the same expected goal that the woman and couple have an ability to be healed after such a loss experience.

A careful assessment of the woman's and family's requirements and situation could be a designated responsibility in each unit of the continuum (e.g. DI, ER, Obs). Interdisiciplinary care follows immediately, again with the knowledge that it is the woman's right to make decisions which are appropriate for her and the family, including unique features such as those relating to culture, ethnic and religion/ spirituality. Whenever possible, all members of the multidisiplinary team - presumably trained in grief counselling ("Despite the plethora of research and theoretical articles to convey needed elements of bereavement care ... there is a need for health care professionals to be educated in perinatal bereavement care."[4]) - spiritual/pastoral care, social worker, physician / midwife, nurses, etc, are actively engaged in providing complete support, with continued assessment of the parents' ability to assimilate the program and knowledge. This can include giving a pager number to the woman and partner, which confirms that immediate support is available. The family physician should be notified as appropriate. In cases of fetal death diagnosis where the woman has the choice of immediate induction or later delivery, extra care will be taken to see the woman weekly if she chooses to carry a baby she knows is dead.[3] Along with an opportunity for a naming/ blessing or baptism ceremony, parents are provided with positive memory making opportunities - which may include seeing, holding, naming their baby - irregardless of gestation age. As is usual, mementos such as photos, identification bands and cards, hair lock (with permission - see above), foot/hand prints, physical records (time, weight, length), names of attending personnel. As well, grief literature should be provided to the bereaved parents and to the family and friends. Caregivers will be the ones to spot if one or both parents would benefit from professional bereavement counselling, and at the least this information should be given to the parents. There is little research on the benefits of spending extra resources on specialized bereavement counsellors in comparison to that available when the perinatal team provides sensitive and skilled perinatal care.[31] At the same time, there is little doubt that certain parents would benefit from professional bereavement counselling.[24,31]

Support groups have proven most effective when designed specifically for parents who have experienced fetal demise, as "...support is often viewed as most credible when it comes from someone who has previously experienced and successfully managed a similar crisis."[24] Parents tend not to join a

bereaved parents' group unless it is specifically for those who have experienced perinatal death. [27] While some parents may use such a support group and others may not, information should be readily available for all parents, and all members of the team(s) in the continuum should be aware of support groups and encourage their formation where none exist. In concert with a physician visit a few weeks after discharge, a team member should meet with the patient to discuss how she and/or the family is coping and also to review the normal feelings following such an event. A final follow-up visit/contact would occur two or three months after the death:[3] "Follow-up contacts are intended to provide ongoing support, assessment of the patient's and family's coping styles, and information. When necessary, referral is made to support groups or mental health counseling."[Midland,14]

While many of you are familiar with pregnancy and infant loss resource materials and helpful brochures, may I recommend a site which is particularly user friendly, and where you can download material for your own use. It is close at hand in Nova Scotia, out of the Annapolis Valley Health Authority. The site, which I recommend for its fulness and sensitivity and good direction, is www.avdha.nshealth.ca/programs/pregnancy_loss.asp

Equally and perhaps even more important, is that standard of care applies to the staff as well as to the patients. Often overlooked, we cannot avoid the fact that wherever we are on the continuum we are facing a sad event which impacts on our own health. Fetal death is a tragedy experienced by hospital staff as well as parents. It is far too easy to lose the spiritual dimension in our own space. The cumulative effect can lead to a loss of meaning in our work, and even alienation from those things which meant so much. In our practices, and in the structures of our practice, who heals the healers? The first stage of healing is one of recognition. Spiritual distress has similar characteristics to work stress and ethical conflict. We tend to avoid the cumulative impact of our sensitive work. If the issues concerning stress are not addressed properly, we will become disillusioned with everything around us, and lose our own self-esteem. Medically, there is a positive correlation between self-esteem and health.[47] None of us in this room can escape what others would call "the human grief" which surrounds us. Those of you who have been around a while know that it can have a cumulative effect. Often it is not recognized, even or especially by ourselves. The statistics for those who are on sick leave are profound. Perhaps the worst offenders are the places of special care like where we work - which can have tragic consequences for us, and therefore for our patients: "Hospitals and other medical centres are beginning to address the need to recognize grief experienced by staff.... There is a consensus that patient death and the subsequent grief experienced by health professionals is a significant issue and the importance of addressing it is increasingly being recognized." [48]

As noted at the beginning, spiritual care is critical in our approach to loss, specifically in cases of fetal demise. In the larger picture, spirituality is becoming front and centre. We are learning that while spirituality may become sharper when faced with ultimate moments - ours or our partners, friends, family, colleagues or patients, its development begins and belongs in our work, home life and play. We are engaged in best practices - the best practices in life. We are called to give and live life in its fulness - to put meaning into living, hope into a future, life into dying, love into caring, and Spirit into all that we do and are!

11. CONCLUSION

Appropriate grieving over fetal loss is important. As promised at the outset, I will end by relating a remarkable story. [17] A funeral home had decided to sponsor a grief group for people who had experienced stillbirths. The meetings were to be held in a study at the funeral home the first Monday of each month. About the time the very first meeting was to start, a senior lady wandered into the funeral home. Thinking she had come for a 'viewing', the funeral director approached her.

"No," she said, "I'm here for the grief group. You see, sixty-one years ago I delivered a stillborn baby boy. My husband took him and buried him before I even got out of the hospital. I didn't even get to see him. My husband came into my room at the hospital and said, 'The baby's gone. I've buried him, and I never want to hear you mention it again.' So, for the last six decades I've mourned for that little baby inside myself.

Well, four months ago my husband died... and I'm here to talk about my little boy.... I named him Randy... and you're the first person I've ever told."

There are four notes which I would like to include at a later date ... perhaps under the headings:

1. SEEING & HOLDING THE FETUS: A CONTROVERSY?;
2. FETAL ANOMALIES;
3. MEN ARE PART OF IT TOO;
4. GETTING PREGNANT AGAIN. Perhaps someone else can add these notes.

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