Going Home

by Jill Wilke, Resolve Through Sharing lead educator

I don’t recall a period in my life that doesn’t include the lake. Every summer, my parents, sister, and I would load up our big, green station wagon and happily drive 15 hours southwest to my grandparents’ second home on the Lake of the Ozarks in Missouri. The lake was a magical place for a kid from New York: towering oak trees, bumpy dirt roads, and miles and miles of warm lake water.

My sister and I loved riding in our grandfather’s World War II Army jeep, the warm wind blowing through our hair, to get the mail (and beg for penny candy) up at the little general store. “The store,” as we called it, was the place where you got bait, gas, tools, food, rented movies, and socialized—a one-stop location for everything you needed. We spent our days swimming, fishing, going out on the pontoon boat, and “flying” in the jeep, and we spent the evenings playing Yahtzee, roasting marshmallows, and watching fireworks and dances at the Wonderland Camp lake front, nestled in the curve of the cove directly down from our dock.

Uncle Phil’s Legacy
My dad’s only sibling, Phil, was born in 1941. At birth, his body seemed limp, he didn’t feed well, and he had a club foot. My grandfather soon went to fight in WWII, leaving my grandmother and great aunt to raise my father and Phil alone. No one really knew what was wrong with Phil. My grandmother and her sister were suspicious that the doctor who delivered him had caused these issues during delivery. The doctors labeled him “mentally retarded” and said that he would not live past the age of two.

But Phil grew and began to talk and learn, and he was able to attend regular school until the 8th grade. He had outlived his life expectancy and everyone’s expectations but as time went on some unusual characteristics came to light. He began to eat endlessly, never seeming satisfied. He was short in stature, never went through puberty, and had obsessive compulsive tendencies. In his teens, Phil’s behavior became too much for

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my grandparents to manage. He was placed in a center for the mentally retarded but he was always loved, visited, and home for holidays and special events.

It wasn’t until Phil was 36-years-old that my mother read a magazine article that seemed to describe his characteristics. She called my grandfather, a doctor’s appointment was made, and, subsequently, Phil finally had a diagnosis—Prader-Willi Syndrome. After years of frustration and fear, my grandparents finally knew what they were dealing with and could stop wondering who was at fault.

Wonderland Camp

Upon my grandfather’s retirement from General Electric, he decided to start a camp for people with intellectual disabilities like Phil. He purchased land on the Lake of the Ozarks and got to work raising funds for a place that would allow an outdoor experience for those who otherwise (at this time—1969) primarily lived in an institution or at home, out of the public eye. He involved the Missouri National Guard and Jaycee organization and their efforts led to the opening of Wonderland Camp in the summer of 1970.

Today, Wonderland Camp sits on 150 acres of land and provides an outdoor experience for over 1,000 campers every summer. Amenities include a pool, splash pad, wheelchair accessible tree house, arts and crafts room, dining hall, open play fields, mini golf, BB gun range, playground, a giant sandbox, and a basketball court. In addition, a big, red wagon pulled by a tractor takes the campers to the lake front daily for fishing and paddle and pontoon boat rides. There is also a medical clinic onsite.

My sister Lori and I are on the Wonderland Camp board of directors now. Our children have grown up enjoying the area and intend to, one day, serve on the board and continue our grandfather’s and uncle Phil’s legacy.

It’s tradition for everyone onsite to wave as the boats go by. I’ll never get over the joy on people’s faces when they experience a boat ride for the first time, basking in that wonderful, warm sun. My grandfather loved that scene, and I love to see it continuing every summer.

I am happy to say that my husband and I now live in the “lake house.” The house itself has undergone some renovation, but “The store” remains, as well as the dirt road. We had to exchange the jeep for a Kubota but the feeling of flying around the circle road still makes me smile. We head up to the camp several times a week to see what’s going on or to watch the campers play, create, and dance. And we always wave as the pontoon boats go by.

Now, when my car hits the dirt road, I know I’m home…

SAVE THE DATES

This summer, RTS is hosting RTS Bereavement Training: Perinatal Death; Pediatric and Adult Death, and RTS Coordinator Training at Wonderland Camp, whose vision mirrors that of RTS—to help others create meaningful relationships and experiences.

I invite you to join me at “home” in the retreat setting of the camp for a truly unique experience. Details will be posted on the RTS website soon, but for now SAVE THE DATES – August 24-28, Lake of the Ozarks!
5 Things to Do, Say, and Know:
Tips for Coping With Grief and Loss

Resolve Through Sharing (RTS) is proud to introduce a new series, 5 Things to Do, Say, and Know: Tips for Coping With Grief and Loss. A new installment will be posted to our Facebook and LinkedIn pages twice a month. Please like and share these posts with others so that, together, we can build collective knowledge and better help those in the midst of grief.

The content of the posts is not considered all-inclusive, but, rather, is designed as a way of inspiring and stimulating your own ideas for remembering and responding. Each item may be used for educational purposes without alteration and with credit to RTS. Thanks, as always, for reading and sharing. If you haven’t already done so, please go to:

Facebook BereavementServices/ResolveThroughSharing

Meaningful Moments: Ritual and Reflection When a Child Dies now included in bereavement training materials

The book, Meaningful Moments: Ritual and Reflection When a Child Dies by Rana Limbo and Kathie Kobler, is now a text for all three of the RTS core courses: RTS Bereavement Training: Perinatal Death; Pediatric and Adult Death; and Neonatal and Pediatric Death. The book received high praise from Dr. Betty Ferrell, internationally known for her work in palliative care and a founder of ELNEC training. As editor of the Journal of Hospice and Palliative Nursing, she wrote this in a recent editorial:

Rana Limbo and Kathie Kobler are role models for transforming clinical care. Their work in creating meaningful rituals at the time of infant death is profound. [Their book] captures the art of pediatric palliative care.


The book can be ordered at www.bereavementservices.org/catalog/bookstore or by calling 608.775.4747 and then press “1.”

Introducing the newest RTS national faculty member

Amy Creamer, MHC, coordinator of perinatal bereavement at Sisters of Charity Hospital - Catholic Health, Buffalo, NY, is our newest RTS national faculty member. Amy holds a Master’s degree in Mental Health Counseling and provides the patients, families, and staff of her hospital with grief counseling during perinatal loss. Her work as coordinator of perinatal bereavement includes facilitating education within her hospital system, holding burial services for families and postpartum care of families after they are discharged from the hospital. Amy facilitates three support groups at Sisters hospital that include stillbirth, miscarriage, and pregnancy after a loss. Amy also provides individual, couples, and family counseling to families in the Buffalo community.

Amy holds certification in Compassionate Bereavement Care through the MISS Foundation, which emphasizes the ATTEND model of mindful care for patients. Amy sits on the planning committee of the Western New York Perinatal Bereavement Network, which works to improve the care given to patients in thirteen local hospitals. Welcome, Amy!
“Ask Our Experts”

A recent addition to the RTS website, Ask Our Experts Dr. Limbo & Jill, provides a space for discussing topics relevant to bereavement care providers. Using the feature is simple: Click on “Ask Our Experts” on the homepage, send us your question, and then wait for your answer via email. Select questions and our responses are posted on the website (with all identifying data removed). Check this section each time you visit our website as questions and responses are added frequently.

Below is one example of a query we received that allowed discussion of a topic recently addressed in a journal.

**Question:**

There was an article in a recent issue of *Nursing for Women’s Health* by Heather Duffy entitled “Water Immersion in neonatal bereavement photography.” The article contains photographs of babies’ hands with and without water immersion. Is that something that we will want to add to our protocol? Also in the article it mentions the need to have professional photography in order to get quality pictures. At our hospital, we are fortunate to have them available much of the time. I know the staff are thankful when the family gets professional pictures. The question often comes up from staff as to why they need to take additional pictures since the family gets professional pictures. Do you see any reason for this?

**RTS Response:**

These are questions that are important to all care providers who support families by offering photos of the family and their baby. I will address your question about professional photography first.

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Introducing new RTS staff members

Carolyn Bostrack, MBA, LEED AP O+M, Business Development Consultant. Carolyn brings a sales and consulting background from her previous role at Gensler where she works with clients in the design, planning, and implementation of software systems. She has experience with change management, software training, marketing, and elearning in addition to her consulting work. She is a former GHS employee serving in both a Patient Liaison role and HUC for Labor and Delivery, where she first became acquainted with RTS. Carolyn is currently working on completion of her PhD in Organizational Leadership.

**Cha’ Frazier**

Cha’ Frazier came to La Crosse by way of Chicago, IL, almost six years ago. Her background is primarily in program and project management with a customer service specialty. Cha’s educational experience includes a bachelor of science in business management and she is currently studying for a master’s of science in project management at Boston University. Cha’ began her career with Gundersen Health System in September 2011 as a temporary patient services specialist and transitioned to the role of business coordinator for Gundersen Medical Foundation’s Bereavement and Advance Care Planning Services in November, 2013. She is very excited about her contributions over the past year in this role. She is passionate about the work that RTS does and is committed to supporting the efforts that allow us to deliver gold standard trainings all over the world.
There are primarily two well known resources for perinatal bereavement photography: Now I Lay Me Down To Sleep (nilmdts.org) and Todd Hochberg (toddhochberg.com). Both have websites that are inspiring and informative. Both are highly valued by parents and staff. When professional photography services are available by an outside source or internally via your medical media department, there is certainly no reason not to engage them in helping a family choose the photos they would like to have as mementoes of their time with their baby.

RTS continues to devote a portion of the RTS Bereavement Training: Perinatal Death to photography. We believe that staff (in most cases, nurses) need to remain skilled in taking baby and family perinatal bereavement photos. We have noted in the years since outside professional photographers were available that nurses are more apt to think, “A professional will come and take pictures. I don’t need to maintain my photography skills.” Several issues may be linked to this way of thinking. 1) A professional photographer may not be available (e.g., already serving another family); 2) in certain areas of the country, bad weather may prevent the photographer from making the trip; 3) the photographers may have a published protocol that they are not available to families whose baby is fewer than 25 weeks gestation (as a way of managing their time, as they are volunteers and usually have jobs and families).

The RTS program teaches a photojournalistic photography style, which Todd Hochberg does so beautifully. However, the photographer cannot drop everything and essentially move to the hospital to be with the family. It is the nurse—and only the nurse—who sees these families over time and can document relationships as they unfold. The nurse is in a primary position to help families with their own photos—with smart phones being the norm now, in addition to point and shoot cameras, families are typically prepared to photograph their baby. The nurse needs to keep his/her photography competencies so that the nurse can suggest ways that the family may want to create photographic memories and keepsakes. I don’t see the nurse needing to take all or even most of the photos—but should be involved in their creation through guidance and an “eye” for what the family may want to capture.

To think about something as a standard means it’s available to everyone 24/7. There is much evidence that supports photography as a standard practice in bereavement. The only way to guarantee that it remains so is to involve a village: outside photographers whom parents contact and make arrangements with; unit-based nurses who remain competent through practice and by reviewing how to take photos (e.g., the RTS manual); and photographers from an organization’s medical photography service. Anyone doing perinatal bereavement photography needs to understand that photos capture relationships and that’s the story that needs telling. Nurses see these stories unfold every time a baby dies. It truly is a privilege to be a photographer.

Regarding the article you mention, there doesn’t seem to be additional evidence that supports this method. However, that doesn’t mean you shouldn’t try it and evaluate the results. If you find it to be an effective method, then by all means, add it to your policy or standard operating procedure and use this article as documentation.

Rana Limbo, PhD, RN, PMHCNS-BC, CPLC, FAAN
Remembrance Service Inspiration

Thank you to Yolanda King, RTS coordinator at MedStar Washington Hospital Center, Washington, DC, for sharing the program and photos from her recent remembrance service with us. We know that so many of you are mindful of what these services mean to parents and devote time, creativity, and many other resources to develop an intimate, inspired event. Yolanda hopes that you will glean new ideas for an upcoming service, including how to design a bilingual program for a diverse group of families and those close to them.

2015 RTS Bereavement Training Schedule

**RTS Bereavement Training: Perinatal Death & RTS Coordinator Training**

- March 25-27  – Bolingbrook, IL
- April 14-16, 2015  – Edison, NJ
- April 28-30, 2015  – Matthews, NC
- May 28-30, 2015  – San Luis Obispo, CA
- August 11-13, 2015  – Hanford, CA
- August 25-27, 2015  – Lake of the Ozarks, MO
- October 6-8, 2015  – Lynchburg, VA

**RTS Bereavement Training: Pediatric and Adult Death & RTS Coordinator Training**

- June 10-12, 2015  – Des Moines, IA
- August 27-29, 2015  – Rocky Mount (Lake of the Ozarks), MO

Trainings at other locations in 2015 are being planned. Please go to www.gundersenhealth.org/resolve-through-sharing for the most up-to-date schedule.

Interested in bringing RTS bereavement training to your organization? The Sponsorship Model might be right for you

The sponsorship model is a closed-to-the-public option tailored for organizations that prefer to network internally. Organizations who might find this model alluring could be, but not limited to, large health systems, partner organizations, and military.

For more information on how to bring RTS training to your hospital through the Sponsorship Model, or to learn about other options, please contact Carolyn Bostrack at ccbostra@gundersenhealth.org, or 608.775.3568 | 800.362.9567, ext 53568
Certification in Perinatal Loss Care

For many years, professionals in the field of perinatal bereavement knew their specialty area was one with substance and depth. Yet there was not an official way of acknowledging our expertise. Thanks to the Hospice & Palliative Credentialing Center (HPCC), that has changed. The perinatal loss certification exam, first offered in 2013, provides the credential CPLC (Certified in Perinatal Loss Care) to those who successfully pass the exam. The exam is interdisciplinary, written for all professionals a) with at least 2 years’ experience of caring for women/families experiencing perinatal death and b) holding a professional license. Examples of candidates for the exam include the disciplines of nursing, social work, chaplaincy, psychotherapy and counseling, medicine, and child life.

To learn more about the exam and to review the candidate handbook, please use this link: http://hpcc.advancingexpertcare.org/competence/perinatal-loss-cplc/

A new organization name, new website, and a lovely lapel pin available for purchase signal the beginning of the 3rd year of the Certification in Perinatal Loss Care (CPLC). Kathie Kobler, RTS national faculty and recent past president of the Hospice and Palliative Credentialing Center, has provided leadership in this important aspect of professional credentialing and competency development.

RTS is proud to announce that at the end of 2015, our entire national faculty will be credentialed through HPCC. Many of those with current CPLC credentials are RTS-trained.

We are grateful to HPCC for helping to create the highest level of competency development through this one-of-a-kind exam. We encourage all of you who are experts in this field to become certified. It is a statement of your expertise and builds awareness of the critical nature of this work.

You will find that RTS training is listed as the only current educational offering to help fully prepare for the exam.

Dahlberg Award: Dr. Rana Limbo to deliver keynote about developing and sustaining relationships

There is little discussion of how one develops relationship competencies and the personal and professional outcomes of doing so. Through the use of video, case studies, and substantial research findings, Dr. Limbo will frame building relationships around the model of guided participation. This keynote discussion spans Dr. Limbo’s career caring for new mothers and infants, teaching nursing students, working with babies with very low birthweight and their families, many years of educating professionals, and supporting families when a baby dies.

Gundersen Health System’s Rana Limbo, PhD, RN, PMHCNS-BC CPLC, FAAN, will receive Gundersen Medical Foundation’s Dahlberg Scholar Award and deliver the keynote address at Nursing Research on the Green, Thursday, April 23, at Viterbo University Fine Arts Center, La Crosse, WI. Nursing Research on the Green, which celebrates and recognizes excellence in nursing runs from 9 a.m. to 3 p.m. The award presentation and keynote address will begin at noon.

In addition, don’t miss the Dahlberg Scholar Reception at 11 a.m. where a light lunch will be served.

Pre-register by April 13

For scheduling purposes, those interested in attending are encouraged to plan now. To pre-register, go to www.gundersenhealth.org/nursing and select Nursing Research on the Green from the Events menu in the right column.

There is no charge to attend and nursing contact hours are available.
Third Core Course!

RTS is proud to announce the introduction in fall, 2015, of our third core course: Resolve Through Sharing (RTS) Bereavement Training: Neonatal and Pediatric Death.

This blended learning course with online learning and two days of classroom provides you with a rich educational experience to develop or enhance your knowledge, level of skill, and personal awareness when providing bereavement care when a newborn baby or older child dies. The course completes a training roster that has been developed, refined, tested, and offered to an international audience, beginning at Gundersen Health System in 1981.

Who should attend?
Nurses, social workers (all levels of practice), chaplains, midwives, genetic counselors, physicians, nurse midwives, nurse practitioners, physician assistants, child life specialists, ultrasonographers, public health nurses, home health visitors, and funeral directors.

Resolve Through Sharing (RTS) Bereavement Training: Pediatric and Adult Death

This blended learning course with two days of classroom training and additional online learning provides you with a rich educational experience to develop or enhance your knowledge, level of skill, and personal awareness when providing bereavement care when a child or adult dies.

Who should attend?
Nurses, social workers (all levels of practice), chaplains, midwives, genetic counselors, physicians, nurse midwives, physician assistants, child life specialists, ultrasonographers, public health nurses, home health visitors, and funeral directors.

Resolve Through Sharing® (RTS) Bereavement Training: Perinatal Death

Our first core course and the one we are best known for, this blended learning course with two days of classroom training and additional online learning provides you with a rich educational experience to develop or enhance your knowledge, level of skill, and personal awareness when caring for families whose baby dies at any time during pregnancy, with a life-threatening condition diagnosed during pregnancy, at birth, and shortly after birth. The content includes caring for others and caring for yourself, a key component of bereavement care.

Who should attend?
Nurses, social workers (all levels of practice), chaplains, midwives, genetic counselors, physicians, nurse midwives, physician assistants, child life specialists, ultrasonographers, public health nurses, home health visitors, and funeral directors.
Research

RTS Connection always contains highlights of new research that help coordinators and support persons maintain their goal to provide the best possible care to families when a precious loved one dies. Evidence-based practice is much more than a clichéd phrase; rather it points to professionalism, high standards, and a way of solidly linking thought and action.

Charlotte Wool, PhD, RN, is becoming widely known for her research in perinatal palliative care. She recently posted an invitation to parents on the perinatalhospice.org website, which we include here. We encourage you to provide Dr. Wool’s invitation (below) to any parents you know who may be interested in participating. You may want to include it in your program’s newsletter, at parent support group, through your perinatal palliative care service, or through social media such as Facebook. Dr. Wool is building a remarkable program of research to guide all of us to be understanding, aware, and able to provide the care that patients and their families need.

Dear Parent,

Greetings. My name is Charlotte Wool and I am a nurse researcher and a former labor and delivery nurse. I have a heart for families who have suffered through the loss of a child.

I am asking for your help to improve the way health care is delivered to parents who have been given a life-limiting prenatal diagnosis. A life-limiting condition means that something happened that caused the developing baby not to be healthy enough to live a normal life.

If you received news during your pregnancy that your baby had a serious life-limiting condition and you chose to continue the pregnancy, you are invited to participate in this survey.

If your baby died, I want to express my heartfelt sympathy. I am so sorry for your loss. I am certain you loved your baby deeply. Accepting this invitation will:

1) Give you a chance to voice your feedback about the care you received after you learned about your baby’s condition
2) Give doctors, nurses, and other health care providers information about how to improve their services.

The link to the survey is https://www.surveymonkey.com/s/TheVoiceofParents

Mothers and fathers are welcome to complete the survey and should do so separately. Everyone is eligible to win a $100 gift card to Target if you enter a drawing at the end of the survey. The survey should take about 20 minutes to complete, longer if you chose to give written comments.

Everything you share is private and will be kept completely confidential.

You are welcome to email me if you have questions. I can be reached at cwool@patriots.uttler.edu

Thank you in advance for your time and comments. I am looking forward to hearing your feedback.

With Kind Regards, Charlotte Wool PhD, RN

Dr. Marianne Hutti’s and colleagues’ research on grief intensity, which is summarized in the RTS perinatal training, has focused on development of the *Perinatal Grief Intensity Scale (PGIS)*. Hutti’s work is clinically useful as she has identified three important factors related to grief intensity following perinatal death: High Grief Intensity is associated with **HIGH Reality** (Pregnancy and baby are real to parent); **LOW Congruence** (actual experience of perinatal death is nothing like the parents would want it to be, given that they had to go through it), and **LOW Confront Others** (they feel powerless to do anything about it).

Low Grief Intensity is associated with **LOW Reality** (neither pregnancy nor baby are perceived as less real) (Perceived as vaginal bleeding); **HIGH Congruence** (Loss experience is unfolding exactly as parents perceive that it should), and if it does not, they have **HIGH Confront Others** (They feel able to tell significant others what they need, and what they do and do not want). The latest study supports the practice of screening, construct validity of the PGIS, and the intense emotion both partners face after the death of a baby. The study supported the belief that reality of the pregnancy tends to be more divergent with miscarriage (Wilke, J., & Limbo, R. (2012). Resolve Through Sharing® bereavement training : Perinatal death, (8th ed). La Crosse, WI; Gundersen Lutheran Medical Foundation, Inc.)


The authors provide an interesting background and findings in this research describing metaphorical language used by grieving couples following the death of a child. Being aware of how couples may convey aspects of their relationship using metaphor helps care providers listen better and perhaps make sense of where individual members of a couple express same or divergent descriptors. The researchers described the interesting idea that couples frequently used metaphors that included a dynamic process, particularly using language that pointed to “journey.” These findings are consistent with research involving individuals in which the same or similar words were used such as “I’m not sure where this journey will lead.” The authors point out the value in metaphorical communication to bridge difficult times of disconnection between couples and increased understanding between the couple and those caring for them (bereavement support person or psychotherapist).

The URL below will take you to an article on expertise. We at RTS encourage you to read the article and reflect on these questions:

1. What is your response to the article?
2. What does being an expert entail?
3. How did you develop your expertise?
4. What changes, if any, did this article make in your understanding of being an expert?

We invite you to share your responses to the questions with us via email at berservs@gundersenhealth.org. We look forward to hearing from you and summarizing your comments in an upcoming issue of RTS Connection.

http://thefederalist.com/2014/01/17/the-death-of-expertise/