Offering options to families

Question
We currently have a policy to require consent to photograph as has been recommended by the RTS national office. And we have a policy to keep unwanted mementos/photos on file with the RTS office of our hospital for 1 year.

Does your hospital keep the bereavement photos as part of the medical record? If not, what would be done in case of fire or loss of photos if parents asked for in the future? Now that we require the consent, I am wondering if parents’ expectations might include that we would have these on file for the future. We do not tell our patients that we will keep them on file unless they decline them, in which case we give them up to 1 year.

I am trying to determine the best practice for storing digital photos even when the parents sign for and accept the printed photos and/or CD. Your recommendations and current practices are requested.

Answer
Safe storage of photos, provided as mementos for a bereaved family, is of utmost importance.

Generally, there are two ways of taking photos of babies or older children who died. One is parent-led, using a professional photographer of their choice whom they invite into the hospital (e.g., Now I Lay Me Down To Sleep) or taking the photos themselves. Alternatively, hospital staff may take photos using a hospital camera.

Some hospitals rely on filing and storing actual copies of photos. Some parents may choose not to take the original photos and unit staff or a bereavement coordinator will store those photos for a stated period of time (e.g., one year). The time frame is usually determined by how much storage space is available for hard copies of the photos and/or compact disks. Some RTS professionals have RTS family files in a cabinet where they keep copies should a family lose the originals or decide they want these photos. Some hospitals give the SD card from the digital camera to the parents, with instructions for safe keeping and back-up copies (see below).

At Gundersen Health System, the SD card from the digital camera (usually used by a nurse) is given to a photographer in our Medical Media (MM) department. Staff from MM make copies for the family and create a labeled CD with all pictures taken. The originals are stored, with the mother’s medical record number as identification, on the hard drive of a computer in MM. If ever a family would need additional copies, due to flood, fire, or theft, they would have access to get copies from MM.

Whether the photos are taken by hospital staff members, parents or family members, or both, the safest and most secure way to store such precious memories is digitally. The previous paragraph describes how this is done within a hospital. Because we have had experience with parents losing their photos, we have these recommendations for how they store photos:

- Create a CD of all photos, along with actual prints, allowing them to securely store one or the other
- Purchase a small fire-safe document box
- Ask a family member or friend to safely store a back-up copy.
Question
1. Do you recommend parental consent for photography? 2. What about storing the memory box and photos if mom is not ready to take them home. What do recommend as a secure place to store this patient information? 3. How do you assure camera memory card is secure? 4. Do you have a policy that can be shared?

Answer
Bereavement photography is an issue that is multi-faceted. Thank you for asking for clarification on several aspects of the process. First of all, the manual for the Resolve Through Sharing® Bereavement Training: Perinatal Death training contains a great deal of information on bereavement photography.

RTS has been involved in writing policy, SOPs, and manual updates on photography since 1981. During that time, practices have changed as digital media became the norm, most bereaved parents and/or their family members have hand-held electronic devices with cameras, and the organization Now I Lay Me Down To Sleep (NILMDTS) is an important presence in many hospitals. I will respond to each of your questions in the order you asked them:

1. Yes, we recommend consents if anyone other than the parents themselves (or their designee) take the photos.

2. This is a question that is more frequently asked now that a) some mementos have been with RTS coordinators for many years, and b) storage is at a premium in most healthcare organizations. The option that we prefer is that the parents assume responsibility for anything that belongs to them. There is an important caveat with this: Care providers need to sensitively give them their keepsakes (including photos) in something that is closed (we prefer the purple memory boxes from Memories Unlimited) with the suggestion that they can place the box in a safe place and open it when the time is right. They do not have to see the photos or other keepsakes until they feel ready to do so. Parents may select a family member or friend to be responsible for the memory card, stick, or disk and other keepsakes if they are not ready to see them initially. Gundersen does not store any keepsakes, other than the digital photos in the electronic health record.

3. If you provide a memory card for your hospital camera and then give this card to the parents, they would be responsible for it once it is in their possession. Digital pictures can be put on a disk as well. At Gundersen Health System, where RTS began, medical media will put the pictures on a disk for the family and actually print a copy, too. They store the digital photos in the mother’s EHR as a back-up method for emergencies or reprints.

An alternative, when possible, is that parents provide their own photographic equipment. This may be a cell phone, tablet, computer, digital or other type of camera with a memory card or stick. We would not expect them to sign a consent form if they are using their own equipment for photos.

Alternatively, many hospitals encourage parents to call NILMDTS to make arrangements for a photographer to come to the hospital and take pictures of their family. At Gundersen, the hospital staff members do not make the arrangements with the NILMDTS photographer; rather the parents themselves do that. Our hospital’s legal experts advised us to place the family in charge of these arrangements. In that sense, the photographer is a visitor, invited in by the family.
4. A photography policy would likely be included within a policy (or Standard Operating Procedure) for perinatal, pediatric, or adult death. It should include a) a consent form if photos are taken by hospital employees, b) a list of photography options for parents, c) the contact information for NILMDTS (as appropriate), d) how digital photography is managed (e.g., parent-provided or employee-provided memory card, stick, or disk, e) use of family’s own photographic equipment, f) storage of keepsakes and photos. We recommend that you use the standard consent for photography form that is available from your own health care institution. This would meet your risk management and compliance guidelines.

Question
I am reaching out to see if there is any research or evidence based practice on the subject of where within the hospital care should be provided to postpartum mothers of either stillborn babies or miscarriages. Currently our hospital does not have a policy in place; the decision is generally left up to the providers whether the patient is transferred from L&D to our mother/baby unit or upstairs to our Med Surg Unit. The nursing staff feels that the Med Surg unit would be best because there are no infants to trigger emotions, however our providers prefer them to go to mother/baby because “we can provide better care.” Do you have any opinion or knowledge of where is best for the patients long term mental health? Thank you.

Answer
Your question is not an uncommon one. I am not aware of specific research on this topic but as you mention, there are emotional triggers for families who stay on the postpartum unit. Here is what RTS suggests and what we do at our home hospital, Gundersen Health System.

We offer the option of recovering on postpartum or on a medical surgical floor to the patient.
- In either case, we put up a door indicator card that reminds staff that a death has occurred.
- We have a core group of nurses that are RTS trained on the medical/surgical floor to care for patients choosing to recover there. Our chaplains and social workers throughout the hospital have RTS training so the interdisciplinary care will still be available. Of course the primary chaplains and social workers on post-partum can go to the Med/Surg floor to see the patient.
- Postpartum staff will assist the Med/Surg staff when necessary (i.e. discharge teaching, peri care, etc.).
- Some parents prefer to stay in post-partum to acknowledge their parenthood.
- Some parents prefer to stay in post-partum because of the staff expertise as you mentioned.
- If the patient is staying on post-partum we try to place them in a quieter area if possible

The key to supporting the patient is having educated staff present. The door card is crucial in reminding staff to be mindful, even the physicians. If the patient is staying on postpartum they need to be prepared that they may hear cries. They should also be aware of the door card. Most find this comforting. I hope this helps. Let me know if you have any other questions.

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 is 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?

Answer

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.

There are primarily two well-known resources for perinatal bereavement photography: Now I Lay Me Down To Sleep and Todd Hochberg. 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 mementos 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.