Butterfly's Embrace

A Perinatal Palliative Care and Loss Program

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St Luke’s Health Care System
Executive Summary

Butterfly’s Embrace, a perinatal palliative care and loss program has been in effect since July 2012 and has cared for the population of parents who have experienced perinatal loss. This is a difficult population to serve as our culture is not tolerant of discussing death in general and especially the death of children. When a parent is informed of a perinatal loss, they are suddenly in unknown territory with decisions to make for a grief journey. Gold (2007) summarizes after reviewing the experiences of 6200 bereft individuals “parents have demonstrated that health care providers can make families feel either supported or helpless after their infant dies” (p 230). Due to the stressful nature of the death of a child, Gold (2007) relates that “seemingly benign missteps by a health care provider may be engrained in a bereaved parents memory replayed over and over in years to come” (p 230). This has potential to affect the way these parents of loss will feel about their providers and the institution that served them during their loss.

Yet many parents experience it. Estimation’s best concurrence is that 20%-25% of all pregnancies end in loss and 50% of all women in their reproductive lifetime will experience such a loss (Price 2008). This is a surprising statistic and places weight on the need to serve this population well with our mission of improving the health of people in our region extending to the general health of parents of loss in our community of Boise, Idaho. This program also reaches to extended areas in the State of Idaho within a 120 mile radius of St Luke’s Downtown facility. Evaluation of the program has produced data which supports successful appraisal areas, suggestions for improvement and expansion and estimation of budget requirements for the future.

Data contained in the patient documentation records produced information that could be analyzed regarding how the program in place at St Luke’s was able to help this population
navigate their journey after grief to a healthier and supported life after loss. The data suggested continued relationship with St Luke’s and philanthropy despite devastating loss experiences. Educational activity to the providers of that care was also evaluated and finally, feedback was obtained from the medical provider community as to how this program may have been helpful or, in other cases, negative in their perspective of how they appreciate the program themselves or witness their clients after they were affected by support from the program.

Overwhelmingly viewed as positive by most who participated in the evaluation including, those receiving the services of the program, those providing the services of the program as part of the interdisciplinary team and physicians who care for this population, the program, as all programs, has ability to improve and grow in quality and quantity, serving better. Palliative nursing leadership is at the heart of the success of this program thus far. Tenets of palliative nursing leadership noted in the position statement from the Hospice and Palliative Nurses Association (Dahlin, Reifsnyder, Malloy & Friedrichs 2015) based on the Institute of Medicine report, Dying in America- Improving Quality and Honoring Individual Preference Near the End of Life (IOM, 2014), are a blueprint for helping the palliative nurse leader to create and implement innovative care delivery models that are aligned with the Triple Aim to respect patient and family goals of care while at the same time lowering costs and improving satisfaction with care. Palliative nurse leaders demonstrate clinical excellence with proactive communication that advances care in serious illness and educates in local, regional and national venues. They perform self-assessments of teaching skills and engage in quality improvement projects to evaluate and improve systems and practices related to patient care, palliative care and outcomes. Leadership is also demonstrated by actions that promote access to palliative care, remove disparities in palliative care and assure quality in palliative care. This report depicts that duty.
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According to the CDC (2012), "evaluation is the only way to separate programs that promote health and prevent injury, disease, or disability from those that do not; it is the driving force for planning effective public health strategies, improving existing programs and demonstrating the results of resource investments" (MMWR, Framework for Program Evaluation in Public Health, 1999, pp. 34). Butterfly's Embrace, a perinatal palliative care and loss program has been in effect since July of 2012. Evaluation of the program is timely and suggests accountability for achieving measureable health outcomes from the investment of having this program available to the population of parents who experience a perinatal loss. This includes early pregnancy loss, ectopic pregnancy, and stillbirth, termination of a pregnancy with a known fatal outcome or desire to carry that pregnancy to term and face bereavement during and after birth or during the neonatal period. Evaluation seeks to improve and differs from research which seeks to prove (CDC 2012). The worth of this program is reviewed in a mixed methods manner to observe from different perspectives the needs for improvement, expansion or containment.

Before the program had begun, a population health assessment in Boise, Idaho was accomplished and gaps of care were identified which were the driving force for program planning and implementation. Population constituents and care providers were involved in the initial population assessment and are a part of this program evaluation as well.

A logic model is a tool for program evaluation and is basically a diagram showing the relationship between the resources needed and the activities produced with the work achieved and the immediate and long term outcomes of a program or service (Issel, 2009, pp. 275). Logic models are concise by intent and identify and describe the program design with goals and
objectives reviewed while the program evaluation will substantiate the activities, immediate outcomes and long term outcomes to the extent possible with the credible data that is available.

Table A

*Logic Model of Program for Butterfly’s Embrace*

<table>
<thead>
<tr>
<th>Assumptions</th>
<th>Input</th>
<th>Activities (1 year)</th>
<th>Outputs (1 year)</th>
<th>Immediate Outcomes</th>
<th>Long-Term Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improving health in the region including perinatal loss parents is important to the Community, St Luke’s Health Care System, Providers and Parents themselves.</td>
<td>.3 FTE Position for coordinator of PPC &amp; Loss who has training, education and compassion</td>
<td>Face to face, appointments, at least one hour in length</td>
<td>242 patient follow up phone calls</td>
<td>Parents are supported from diagnosis through bereavement when they experience a bad outcome of pregnancy or the death of their child through early pregnancy loss, stillbirth, neonatal death or SIDS by a team well informed of their needs who can provide relationship based care</td>
<td>Improved mental and physical health of parents after experiencing PPC or Loss</td>
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<tr>
<td>Brochures Books Supplies</td>
<td>Face to face, phone, mail, social media and email interaction with patients, care providers, the interdisciplinary team and community agencies before, during and after loss</td>
<td>103 letters or mail correspondence reports or support letters to patients or providers</td>
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<td></td>
<td>Expressions of gratitude through continued relationship and satisfaction with the institution and providers and/or philanthropic gifting despite devastating loss/grief experiences</td>
</tr>
<tr>
<td>Staff trainings</td>
<td>Face to face, phone, mail, social media and email interaction with patients, care providers, the interdisciplinary team and community agencies before, during and after loss</td>
<td>83 blog posts for 89 members of social media with monitoring of site done @ least 3x’s/week</td>
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<td>Populations who do not have this support currently request these needed services in the future, including pediatric and infertility populations</td>
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<td></td>
<td></td>
<td>48 Legacy Build a Bear recordings and/or bears</td>
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<td></td>
<td></td>
<td>10 Staff trainings</td>
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<td></td>
<td></td>
<td>See logs for other outputs considered essential for operating the program</td>
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Study Design and Data Collection Methods

Evaluation requires credible data collection methods and thought for evaluation was considered at the time of the program launch. Built into the documentation in patient records was the ability to retrieve key evaluation data regarding how the patients themselves viewed what at St Luke’s helped them the most collected as they navigated through the bereavement time that followed their pregnancy loss. This qualitative data was collected, reviewed, analyzed and coded and then themed.

Key information regarding worth of educational trainings for staff was collected in an area new to exposure to the program (prior to and after the trainings done in Twin Falls, Magic Valley St Luke’s in February, 2015) with collection of data at two points, before and after completion of the educational offerings. This information provides insight into the benefit of the training of clinical care providers who care for, but also experience their own grief, when caring for this population. Data gathered was specific to comfort of care providers when dealing with this population of parents of loss before participation and information about ability to use new tools after participation in the educational offering. They were queried as to their knowledge about certification in this field as well with intention of promoting certification in the area of perinatal loss care for those who already have expertise contributing to a team with qualified proficiency.

Medical providers were included in the evaluation process by completing a survey that requested their opinions regarding perceived benefit versus negative affect to themselves or their patients from their observance and perspective if their patients participated in the service for perinatal palliative care or bereavement support after loss provided by the program. They were questioned regarding their knowledge of the full scope of the program, if there were any
improvements they desired from the program and offered the opportunity to add or subtract to the program if they wanted to include that information. They were also provided anonymity without any identifiers on the surveys. Survey tools were delivered personally in hope of a better return rate.

Prior to utility of this data, an inquiry for review of the project was requested from the Medical Director for Research and Medical Education, Dr Mark Roberts. Dr Laura Tivis was also informed of the project request. The project was determined to be consistent with Performance Improvement and did not meet the criteria for human subject research and therefore did not require review of the St Luke’s IRB. The committee did not review it; however it did meet approval as a project and can be reported or presented outside of St Luke’s as long as it is not labeled as research.

Limitations of this evaluation include a possible “halo” effect as described by Holloway and Fulbrook (2001). They discuss the complexities of a ‘properly done’ study and include:

In nursing and midwifery research, the researcher may know all of the participants and this previous association may influence the content of the interview. This might contribute to the potential for a halo effect, described above, but on the other hand, it might enhance the interview environment by promoting a more relaxed and friendly atmosphere (p.548).

While this is not research, these were not interviews and the surveys were allowed to remain anonymous upon return, the halo affect could still have influenced the data from the medical provider surveys that were collected or the patient feedback that was obtained. In regards to the post loss interviews done for bereavement support and the data collected at that
time, some of the parents did already know me from in hospital meeting while some had no relationship with me at all prior to the support phone calls.

Evaluation is ongoing and although the whole interdisciplinary team was not asked to participate in data collection for this evaluation, that will be considered in the future for a more robust evaluation process.

Feedback from Program Participants

During the year in review timeframe taken for this program evaluation, fifty-two parents responded to the question, “What at St Luke’s did we do that helped you the most?” This question, imbedded in a support follow up telephone conversation, was transcribed while talking to the parent. The conversation transpired with the parent, in most cases within two weeks of their inpatient loss experience at St Luke’s. Some of the nonspecific but all-encompassing comments included “everything” which occurred fifteen times out of the fifty-two comments and “everyone was so helpful” which occurred six times out of the fifty-two comments.

Mention of the nurse at the bedside being the most helpful aspect of their experience at St Luke’s occurred thirteen times out of the fifty-two comments and there was association of the nurse with the words, care, presence, kindness, sensitivity, compassion, sympathy, emotional attentiveness, knowing and support. The doctor was mentioned along with the nurse in these statements three times.

One of the themes that occurred was the benefit noted by the parents when the nurse held the space to allow time spent with their deceased child. The theme included not being “bothered” during this sacred time, allowed to be “alone” with their child and two of the comments about time spent were complimentary regarding the butterfly room which is available only on the
Meridian campus currently. This comment and theme occurred eleven times in the fifty two comments received.

Tangible items that were provided to the families including blankets, memory boxes, pictures, clothes, build-a-bear heart beat recordings and hand and foot castings and prints were mentioned thirteen times as being helpful. Books specific to the palliative care experience were mentioned twice as being extremely helpful. Some comments regarding these items included sleeping with the blanket for months afterward and being afraid that the smell of their child will fade away from the blanket soon. Associated with these certain items, there were comments regarding giving back to the program in the form of philanthropy three times wanting to make sure that these items would always be available to other parents of loss in our community.

A theme of exceptional communication, listening and providing options, informing, respect, non-judgment and honesty evolved. Contained within this theme was the sense that parents of loss were treated as parents, “It was such a blessing to hold her for as long as we could and to bathe her and have that time with her to parent her. That meant the world to us”, and “I was treated like a real mom and included with the real moms” or “Everyone treated Ben as if he was a person who was important to us” and “she talked to Harley like she was real and really there”. These were all nuances of the way parents experienced communication from their care providers. All in all, this theme was recognized thirteen times within the evaluation question. There were two comments that specifically addressed being called and being able to be allowed to talk about it.

There were four mentionable ambivalent comments and no negative comments by parents. The four ambivalent comments included “Well, we had some time to let it sink in before we came in and I felt like we were doing well before we even got delivered. I feel like
I’m doing fine.”, “Nothing really, I don’t think that anything that was done was helpful really but it was okay, nothing should have been done differently. I was having complications and I think I just self-prepared for the inevitable. But you did okay”, “Nothing, but if you would like, you certainly could call me again in the near future, I would like to talk again” and “I don’t know”.

One of the most complimentary expressions from the evaluation question was “I just knew it was going to be okay and believe me, it wasn’t the experience I was wanting. I was going to be delivering at home with a doula and a midwife but after my first few minutes at St Luke’s, I knew it was going to be okay and it was”. The second most complimentary expression was, “The care we received was outstanding, despite what we were going through, I still notice that it was the best care we have ever received”. The care received by the patients was under the umbrella of the perinatal palliative care and loss program which is provided by many providers and nurses and a multidisciplinary team which has attended the trainings of a two hour course entitled “Having butterflies about butterflies”. This class was given a total of ten times over the course of the year to nurses in labor/delivery, surgical areas, emergency areas and pediatrics and the women’s unit that cares for this population after delivery. Chaplains and Family Practice Resident Physicians have also taken the course.

Educational Evaluation

In February 2015, an opportunity to provide the education from the class “Having butterflies about butterflies” presented in an area that had not previously been exposed to the information that has been ongoing in Boise for quite a few years. This presented a unique opportunity to gather some pre and post data regarding the educational offering that had not been obtained from the exposed area of Boise previously. Sixteen participants (n=16) attended and provided pre information from the class. The participants were mostly nurses with two chaplains
and one physician also present. Fourteen participants were female and two participants were male. Fifteen participants (n=15) provided post evaluation information as one participant was called out on an emergency during the educational offering and did not get to participate in the post evaluation data. The participant ages ranged from 29-73 with the mean age being 48 years of age. Participants were asked how many years they had been involved in the care of the population of perinatal loss parents. Years ranged from 2-27 with the mean amount of years being 10.25 years.

Pre data questioning asked on a scale of 1-5, how comfortable are you when you meet the population of perinatal loss parents? (You’ve just been given the assignment). From the responses given, there were none that said they were very uncomfortable, 37.5% (n=6) indicated they were uncomfortable, 12.5% (n=2) indicated they were not sure, 43.75% (n=7) indicated that they were comfortable and 6.25% (n=1) indicated that they were very comfortable with the assignment prior to this educational offering. Participants were also asked how comfortable are you with your skills/practice/knowledge of options to care for the emotional needs of this population? (I know how to do/say things that help). Of the 16 participants, none of them indicated that they were very uncomfortable. 25% (n=4) of the participants indicated that they were uncomfortable with their own skills. 37.5% (n=6) of the participants indicated that they were not sure of their skill set involving this population. 31.25% (n=5) of the participants indicated that they were comfortable with their own skills and 6. 25% (n=1) indicated that they were very comfortable prior to the educational offering. 18.75% (n=3) of the participants were aware that there is a certification exam for perinatal loss care from the Hospice and Palliative Credentialing Center (HPCC). To my knowledge however; none of the participants were certified.
Post evaluation from the educational training revealed when asked to what extent, if any, did attending this educational program change your comfort level as you project in thought to meeting the population of parents experiencing perinatal loss, 66.66 % (n= 10) of the participants stated they were more comfortable, 20% (n=3) stated they now felt confident, 6.66% (n=1) felt no change in their comfort level and 6.66% (n=1) were still uncomfortable thinking about meeting this population after participating in the class. 40% (n=6) of the participants were able to recall 5 or more new tools/skills or practices that they could use in meeting the emotional needs of the population of parents experiencing perinatal loss. 53.3% (n=8) of the participants could recall 3-4 new tools/skills or practices that they could use in meeting the emotional needs of the population of parents experiencing perinatal loss. 6.66% (n=1) of the participants could remember at least 2 new tools/skills or practices that they could use in meeting the needs of the population of parents experiencing perinatal loss. None of the participants said only one or could not recall anything new as a tool/skill or practice that they could say or do to help this population. 30% (n=5) of the participants would like to repeat the education every 2 years. 46.66% (n=7) of the participants would like to have the information reviewed updated or reinforced yearly and 20% (n=3) of the participants wanted more information and more people to have the opportunity for the information so they wanted the information available at least a few times a year for themselves to participate in again or to add more people to the base who have this knowledge.

Open comments were also appreciated after the class and 66.66% (n=10) of the evaluation tools had added comments on them. Gratitude for the class was a theme as were general comments about how helpful the class actually was. Beyond those were poignant comments that I will share here: “I come from life experience that has not included much death,
and if we experienced the death of a loved one, it was just avoided in our family. Being involved in this perinatal loss “support” class has helped me immensely to view death differently in my personal life as well. I really appreciate this extraordinary opportunity to learn, grow and be of help and comfort to others” and “This is such an emotional time for the families, your thoughts and ideas are very helpful- things I have never thought about before.”, and “Your gentleness and directness is very helpful, you gave skills in order to address the needs of these families”.

Physician Survey

According to the Card file in the Centricity Perinatal QS Office Client Program, there are forty nine medical obstetrical providers on the Downtown and Meridian campuses. Of these forty nine, thirty seven were seen personally in the evaluation period and handed a survey regarding the Butterfly’s Embrace Program. From these thirty seven encounters asking for feedback and with option for anonymity and to return at a later date, twenty one surveys \((n=21)\) or 57% of the surveys were returned to me with data retrieved from both campuses. Data was separated further by dismantling the three page survey and data was combined with like data, not like respondent.

Included in the survey was a cover letter explaining the scope of the service with a follow up question within the survey to ask if the physician was aware of the full scope of the program as stated in the cover letter. 76% \((n=16)\) stated that they were aware of the full scope of the service. 19% \((n=4)\) responded that they were not aware of the scope of the service with one additional comment that they were aware of the service but not the extent of the program as it was “much broader than I had realized” having been educated just by reading the cover letter and 4.75% \((n=1)\) did not respond to this particular question.
Providers were asked from their perspective if they noticed any benefit to themselves personally when the service was provided to their population of parents of loss. All questions had room for yes or no and an area for additional comments to be inserted. 90.4% (n=19) responded yes, benefit was noticed personally by the provider. 4.75% (n=1) declared that they noticed no benefit to themselves personally and 4.75% (n=1) chose not to answer the question. Comments in this area of the survey included: “It allows them (patients) more time to confront the loss and have explanations and comfort from a compassionate provider when I may not have that much time to spend with them.”, “Tremendous supplement to care I have to give, especially regarding emotional support, bereavement information and logistics.”, “Yes, this is an invaluable service to both providers and patients- It’s super helpful in supporting patients through the process.”, “Works very well”, “Invaluable”, “I appreciate the follow up I receive.”, and “Yes, it helps to share the burden with me and to be a support system for the patient.”

Providers were then asked from their perspective, if they noticed any benefit to their patients if they received the service. 90.4% (n=19) responded yes, benefit to their patients was, from their perspective, noticeable. 9.5% (n=2) chose not the answer the question with one of those having the additional comment that they never have follow up with the patients as they were solely in the Laborist role. Additional comments from this area of the survey included: “Patients appreciate the support and to feel like their feelings are validated. My patients have also expressed gratitude for the way in which the remains of their babies are treated.”, “This service is absolutely essential!”, “Grief follow up is very important.”, “Patient was very appreciative.”, “Excellent service for my patients and so helpful.”, “Supportive and nurturing”, “Services provided are extremely helpful to my patients. This service makes St Luke’s a standout in our region (especially compared to St Al’s)” and “Much benefit- they can grieve and
express themselves and receive teaching from someone who understands how precious this life was to them and how painful the loss can be.”

Physician providers were also queried regarding any negative effects noticed by either themselves or their patients from their perspective. 95% (n=20) of the respondents replied no noticeable negative effects personally with additional comments of “none” and “not at all” as the only added information. 4.75% (n=1) was left blank.

Regarding the physicians observing noticeable negative effects upon their clients, 90.4% (n=19) responded no, they had not noticed negative effects as part of their experience with two additional comments in this area suggesting a worry pertaining to their patients who may not want the service. They were “Some patients may not be interested but it’s still important to reach out to them so they know support services are available.”, and “But I would make sure you tailor to each individual patient. Some want a lot of hand holding and some don’t.” Other comments in this area were “None at all, they uniformly thank me for the service and appreciate the care, attention and gifts of blankets or stuffed animals.”, and “No patient has ever complained”. 9.5% (n=2) were left blank, one with the comment from the Laborist role repeated regarding no ability for follow up with parents of loss.

Physicians were given the opportunity to express desire for any changes to the program including additions or subtractions and an area for questions regarding the program. 42.8% (n=9) left this portion blank. 33.33% (n=7) responded “no” or “none” to any change in the program, with related further comment like “can’t think of anything at this time but will let you know if I do”, “great service” and “keep it up”. 24% (n=5) had additional suggestions for the program or general comments or questions. They included: “Do you have additional resource information that I can provide to my patients in the office?” “As new nurses start and any
policies change, make sure everyone is aware (for instance) the autopsy protocol and formal paperwork that is needed to be filled out by the physicians”, “Is the Memorial garden here at the hospital or at a cemetery?”, “Is there a weekend contact?”, “Please ask the patient if they want the follow up.”, “Maybe you should provide a handout regarding this service to providers” “I have had 2 patients receive the service and comment on how compassionate and supportive the care was!” and “Thank you for all this help—it is very beneficial and meaningful”.

Recommendations for Growth and Improvement

At this point, the program appears to be successful yet improvement is always possible. From these last suggestions and questions posed by the medical providers, it sounds as if providing some tools to the physician providers in the form of more resource material might be helpful. My thoughts are to provide a “grief basket” for each clinic to share between providers in that office that would have resources for their patients who are facing loss experiences. These resources could provide specific help for different areas needing attention during this grief journey; a list of grief counselors in the community for referral and a sample of books they could use in their library for patient use, for instance, “Swallowed by a Snake” by Thomas Golden (2000) specifically helping men in their grief journeys and handouts for helping other children when parents are confronted with loss in the office. Providing very small blankets, hats and diapers so the medical providers could acknowledge an early loss for the parents directly in the office with this gift as this could become a very satisfying practice for both the providers and the parents of loss sustaining the relationships these parents of loss have with their providers at an exceptionally vulnerable time.

As an interdisciplinary team, providing care and support for our patients experiencing loss in this community, those needing perinatal palliative care for difficult and life limiting
conditions and teaching the members of society ways to help share and support this population is ethically and morally correct (Limbo, Toce & Peck, 2009). Reaching out with more support to the care providers themselves will help to accomplish this mission.

Another suggestion is to improve the bereavement room facilities for families who experience a loss on the unit in our Downtown facility. Currently Meridian Labor/Delivery has ample room and a newly rededicated space provided through philanthropy dollars however downtown St Luke’s does not have this area. Patients have specifically mentioned how helpful the physical space used for solitude in a non-hospital like environment while with their child after death has been. This area is also feasible in the Downtown facility by moving the area reserved for breast pumping and employee meditation to the current bereavement room and moving the bereavement room to the current breast pumping area which is adjacent to the comfort room preserved for family members waiting on parents of loss. This could make for a change in practice to accommodate all of these families on the North Side of Labor/Delivery during the delivery process, keeping their families close at hand and having the physical space to hold the all-encompassing emotional, spiritual and energy space for their needs of bonding post death. This is also a typically quieter environment and could shield parents from the often and seemingly cruel proximate sounds of healthy neonates coming to life during their experience of loss in a busy labor and delivery unit.

Expanding the scope of the service to parents of pediatric loss is also a consideration based on the success of this program and physicians in the pediatric and neonatal realm that could also benefit from the support that these parents require who journey in the community of parents facing life limiting and fatal conditions of older children and the ensuing grief from this experience. Through activity and discussions in the fetal care board, this realm of expansion is
being requested by pediatricians in the pediatric specialty clinics (Dr Neufeld with support by Dr Janos) and with St Luke’s being the Children’s Hospital in our community, it only seems fair that Women and Children “in the boats first” would be a reasonable consideration for our community. St Luke’s enjoys the support and proficiency of an adult palliative care team already and further spread to the population of parents of older children and children themselves is again morally and ethically correct. Budget considerations for such an endeavor would fall to other than the Women’s Center administration but beg for the sharing of this positive data to improve the health of others in our community.

Evaluation is not a onetime event. Evaluation is a continuous activity that should be ongoing to provide insight into areas that can be improved upon as new evidence is made available and new innovations occur. It is a valuable exercise which promotes continued creativity and thought to enhance what we already do well. Future evaluations will key in on other stakeholders within the interdisciplinary team to acquire different perspectives on improvement, for instance our nurse midwives, social workers, genetic counselors, bedside nurses in labor/delivery, NICU and clinic nurses in the OB/GYN and MFM clinics, nurse navigators in the women’s population, ultrasonographers, chaplains and administration. Opportunity to increase the palpable outcomes of this program are also spilling into the arena of unique families as invitation to support surrogate carriers post-delivery for some expression and acknowledgement of their unique grief journeys is planned for the coming year in the form of lecture and SoulCollage® activity to the post-delivery support groups for the community surrogacy business: A Host of Possibilities. It might be beneficial to plan evaluation tools into the new program for assessment opportunity in the future.
Projected Budget for Butterfly’s Embrace 2015-2016

Based on a budget that realizes equal or increase in need, the following budget is projected for the coming fiscal year and is adjustable in three categorical levels. These include Best/Best, Best Medium and Best Minimal so that control is sustained by administration. Volumes for the service are hard to predict and therefore this impacts the building of a budget in terms of accuracy but looking at history may help to estimate growth needs. 2013 recognized 45 documented loss cases between Meridian and Downtown facilities that were treated in the Labor/Delivery environment. 2014 recognized 70 cases between Meridian and Downtown facilities that were treated in the Labor/Delivery environment. This information was gathered by statistics retrieved from Alice Anderson, our CPN IT specialist for Labor/Delivery. This is a 64% increase with unknown future attribution. Budget for coming year will be based on 75 cases.

The service is also available to patients of early pregnancy loss. This population is very difficult to count for many reasons. In 2010, knowing that we could not capture all of this population in the count, an estimation of 697 early pregnancy losses were recognized between Meridian and Downtown Emergency Room environments in a 9 month period using their electronic record coding as the source. A repeat count has not been done but a trend to move care of this population more often to the surgical areas in the hospital has been recognized. This is advantageous to this population because better anesthesia and pain control are achieved during the procedures associated with early pregnancy loss and creates a better patient experience.
## Budget Proposal

<table>
<thead>
<tr>
<th>Requirement</th>
<th>Amount</th>
<th>Best/Best</th>
<th>Best/Medium</th>
<th>Best/Minimal</th>
<th>Total</th>
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<tbody>
<tr>
<td>Perinatal Palliative Care and Loss Coordinator .3 FTE</td>
<td>12 hours/week @ rate of $38.70 per hour</td>
<td>A merit increase hourly rate to $39.20 per hour + Best/Medium</td>
<td>Occasional extra hours for phone work or parent meetings= 2 hours added per week charged to this FTE with all overtime charged to position 1 and L/D</td>
<td>Charge any extra time to L/D unit and position 1 with unchanging hourly wage</td>
<td>$24,148.80 is realized for Best/Minimal</td>
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<td>$28,173.60 is realized for Best/Medium</td>
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<td>$28,537.60 is realized for Best/Best</td>
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<td>Supplies</td>
<td>To serve 75 cases</td>
<td>Providing “Grief Baskets” to each clinic as resource to providers for parents of loss (at near approximate cost of casting expense last year)</td>
<td>Increasing the repertoire of resources available for some cases</td>
<td>No change in what we provide * partial year comparison, hand/foot castings are now philanthropic compared to within budget from previous years but need to support flyer ads/printing</td>
<td>$1106.95 Best/Minimal</td>
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<td>$1200.00 to this amount</td>
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<td>$1329.56 Best/Medium</td>
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<td></td>
<td></td>
<td>$2525.84 Best/Best</td>
</tr>
<tr>
<td>Travel Expenses for Education to in system outlying communities</td>
<td>2 trips this year to include Wood River and one unplanned system level area in need</td>
<td>Compensated Educational opportunity for PPC/Loss Coordinator for continuing education needs + Best/Minimal</td>
<td>Compensated educational presentation to outside of system + Best/Minimal (St Luke’s shines, palliative nurse leader competency is fulfilled)</td>
<td>Hotel, mileage and meals while compensated during educational offerings to in system areas of need</td>
<td>$400.00 Best/Minimal</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td>$2400.00 Best/Medium</td>
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<tr>
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<td></td>
<td></td>
<td></td>
<td>$4400.00 Best/Best</td>
</tr>
</tbody>
</table>
Bereavement Room Changes as discussed in this report for Boise Downtown

- 1 time occurrence space improvement
- Photography equipment added to room changes + Best/Medium
- If grant is denied, funding from this program occurs, if grant approved funding is combined
- Accomplish with philanthropic dollars available only/ no change without grant
- Budget neutral for Best/Minimal
  - $2500.00 for Best/Medium
  - $3000.00 for Best/Best

<table>
<thead>
<tr>
<th>Totals with ability to mix and match options:</th>
<th>Best/Best</th>
<th>Best/Medium</th>
<th>Best/Minimal</th>
</tr>
</thead>
<tbody>
<tr>
<td>$38,463.44</td>
<td>$34,403.16</td>
<td>$25,655.75</td>
<td></td>
</tr>
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It is difficult to place concrete incoming value on a service that currently cannot show incoming measureable dollars as a balance activity on a budget sheet. Patients experiencing satisfaction during times of failure (sometimes perceived as somebody’s fault), normal grief anger and vulnerability however are invaluable. Having philanthropy flow despite these loss experiences when there is no anticipation of failure or loss by the patient is extraordinary and noteworthy even if the amounts cannot be considered sustaining. Philanthropic dollars are also not reliable as there may be coverage for some periods and then none or unexpected gifting not hereto known or counted upon, suddenly available. Sometimes, looking at dollars that did not need to be paid out from failures can enlighten the worth of a program as well however these cannot be tracked but are real even though amounts must be imagined. When we couple that perspective with seeing sustained relationship with providers and professed esteem of the organization to the public after these losses, value continues to be recognized. Even when these services are not billable, it is morally and ethically correct to provide them.

The care is based on the need of the entire population and is spread between the continuum of emergency departments, surgery departments, both inpatient and outpatient and
clinic care from loss experienced at home by the patients, labor/delivery and NICU, antepartum and post-partum units, women’s units and home health and hospice are also all part of the environment of care. The program therefore has been able to serve the population across the health continuum, over lines of departments, inpatient and outpatient settings, almost system wide and state wide and even outside of the St Luke’s Health System walls when patients may be referred to our Maternal Fetal Specialists, are offered the support of Perinatal Palliative Care at St Luke’s with it being the only service available for this population in the State of Idaho but then return for continued care to their previous providers with continued long distance support from the program. Certainly this is a great reflection on the mission statement of St Luke’s Health System. St Luke’s is represented in good light, good faith and kindly for this service by all who have needed it.
References


