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Holistic Comfort and Bereavement of Families Receiving Prenatal Hospice Support During the Loss of an Unborn Child with Lethal Anomalies

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Holistic Comfort and Bereavement of Families receiving Prenatal Hospice Support
during the Loss of an Unborn Child with Lethal Anomalies

By

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A thesis submitted to the faculty of
Gardner-Webb University School of Nursing
In partial fulfillment of the requirements for the
Degree of Master of Science in Nursing

Boiling Springs

2011

Submitted by:

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Abstract

The purpose of this descriptive study was to explore the grieving process and coping mechanism of families that was faced with the impending loss of their unborn child. Grief is a very lonely process.

The aim of this research is to examine how parents cope with the lost of an unborn child with the aid of perinatal hospices. Giving families a broader range of options in regards to continuing their pregnancy. Each family has a right to choice what option is right for them. Choices should be in the hands of the family in regards to continuing with their pregnancy or termination.

The research was guided by Dr. Katharine Kolcaba, Comfort Theory and Practice, using comfort to guide care at the end of life choices. The study was comprised of a convenience sample of nine women that used perinatal hospice. Data was collected through the use of Holistic Comfort Questionnaire, Comfort with End Life Planning, (Kolcaba, 1991) and Core Beareavement Item (Burnett, 2001).

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Introduction

The nurse is an advocate and educator for families and patients in their community. Registered nurses work with patients and their families' in promoting health, preventing disease, and helping patients cope with illness and even death. There are many tasks that nurses would like not to have to perform such as the holistic care that must be completed when caring for the remains of a precious baby that has passed away. There are emotionally and ethically sensitive areas of providing care to dying babies. Nurses must take cues from the families that they are giving support to; this is stressful for the caregiver as well as the family. However, nurses have a great responsibility as well as a great honor to be in the presence of something so precious and yet so tragic, the birth and death of someone's child. For most people throughout history this situation has been dealt with through silence and denial. Nurses now have more opportunities to offer care to families through models of care. Perinatal hospice is one such model which incorporates the strengths of perinatal diagnosis, perinatal grief management, and hospice care to address the family's needs.

Attachments for most families begin at the time of their first missed period or their first positive pregnancy test. In recent years, however, grief theorists and therapist have embraced an alternative view that emphasizes the adaptive function of retaining bonds with the deceased rather than relinquishing them (Klassk Silverman, & Nickmann, 1996). Looking primarily at qualitative research and cultural studies, advocates of this continuing bonds perspective have focused attention on the frequency with which

bereaved families report ongoing engagement with memories and images of their child for many months or even years after the loss, thus maintaining the attachment (Attig, 2000; Klass, 1999).

The coping mechanism that families use to help them adapt has been the use of more abstract bonding through comforting memories. Perinatal Hospice gives families these types of options. They are able to create memories and positive images of their little ones.

Due to the advancement of preinatal testing, more and more parents are learning the devastating news before their babies are born. The skill to diagnose fetal abnormalities has raced ahead of the aptitude to care for the families and their babies. It was once believed that the best practice was to terminate a pregnancy; and for some families this was and still is the best choice; however, there are a growing number of families for which this is not an option due to personal and/or religious beliefs. Modern hospice care for adults originated in the 1960s. This response was in recognition that end-of-life issues for terminally ill patients were being inadequately addressed with traditional approaches (Saunders, 1965). Over the last 10 years, perinatal hospice services have grown out of great sorrow. It is sad to know that while there is a demand for these types of services there seems to be a void that needs to be filled in the nursing community. Perinatal hospice is a family centered care that will address the expectations of families that choose to continue a pregnancy even after their baby has been diagnosed with a life-limiting condition (Limbo, Toce & Peck, 2009).

Perinatal hospice is a gift of time for many families. It allows the parents to prepare for the birth, life and even the death of their unborn child. The death of a baby

before birth is not uncommon, but how it has been dealt with is; and how it affects the families is very significant. After a prenatal diagnosis of a lethal fetal condition, parents are presented with few options. Families have had to seek out supportive care to continue their pregnancy until the time of spontaneous labor or until delivery is required for obstetric indications. For the families that choose perinatal hospice, the majority of the care lies within the Antepartum setting. They are allowed to grieve, explore life issues and prepare for whatever time they might have with their child (Calhoun, Napolitano, Terry, Bussey & Hoeldtke, 2002). There has been a cultural shift in our society today. Once parents were not encouraged to see or hold their babies, they were told to just forget that they were pregnant. We are now seeing that families want time with those children even if a joyful hello means a sorrowful good-bye.

Previously a baby would pass away and the family would have no knowledge there had been any condition to be concerned with. As early as 12 weeks gestation an abnormal screening can occur. Cheri Shoonveld, a genetic counselor for Fairview Health Services in Minnesota and a spokesperson for the National Society of Genetic Counselors states “families have to make more decisions and have a lot to think about when considering the impact that their decision will have on them and their families” (Shoonveld. 1999 pg 45).

Studies don't specifically track how many families in the United State choose to continue the pregnancy after receiving a terminal prenatal diagnosis, but in Shoonveld's experience, only between 10% and 20% of families go on with the pregnancy after hearing the devastating news (Shoonveld, 1999).

Statement of the Problem

An emotional and psychological ramification of a child death has been well documented while little has been discovered about the bereaved parents and how they have had to deal with the grief process and coping mechanism. Faced with the diagnosis of a lethal anomaly of their unborn child, parents have choices to make in regards to continuing the pregnancy and the bereavement process. According to Rubin (1985) “the bereavement process is judged to be completed when levels of functioning and personality characteristics have resumed in their pre-loss state” (p.353). The standard implies that if the bereavement process is successfully resolved, the person will eventually be the same as he or she was before the death. The focus of the present study is to consider how well families cope with the grieving process when facing the certain death of their unborn child with the assistance of perinatal hospice.

Purpose of Study

The purpose of this study is to examine the grieving process and coping mechanisms in the loss of an unborn child with the aid of perinatal hospice. The proposed study will identify holistic comfort and bereavement of families that have received perinatal hospice support during the loss of an unborn child with lethal anomalies. What were the options the parents had when they received a diagnosis of lethal anomalies?

Noteworthy of this research is to give control to the parents who have been told their unborn baby will not live outside the uterus. By offering parents the choice to continue their pregnancies they will have time to work through the grieving process and

develop coping mechanisms and to bond with their child thus creating memories and making plans on how those last moments will be spent with their child. One father stated...“she wasn’t just alive for eleven days. She was alive for nine months and eleven days.”[A father of a baby with trisomy 18 who lived for 11 days after she was born] (Ramer-Chrastek & Thygeson, 2005 p.274).

“As you do not know the path of the wind or how the baby is formed in the mother’s womb so you cannot understand the work of God, the Maker of all things.” Ecclesiastes 11:5 (Holy Bible).

Research Question

What is the holistic comfort and bereavement of the families receiving prenatal hospice support during the loss of an unborn child with lethal anomalies?

Relevant Terms

Keywords: perinatal care, hospice care, fetal death, palliate care, grief, coping mechanisms, end of life care

Theoretical Assumptions

Kolcaba's Comfort Theory directs nurses to assess comfort needs of patients, design holistic interventions to meet these needs, and measure the effectiveness of interventions to enhance comfort compared with a pre intervention baseline. Comfort is the immediate desired outcome of intentional comfort interventions. Comfort is theoretically related to subsequent outcomes such as improved functional status, increased energy, and enhanced mood. Comfort is defined as the immediate outcome of feeling strengthened when needs for relief, ease, and transcendence are addressed in the context of experience, physical, spiritual, sociocultural, and environmental (Kolcaba, 2003). Effective interventions that are delivered consistently over time were demonstrated to be strongly correlated with increased total comfort over the same period (Novak, Kolcaba & Steiner, 2001).

Conceptual Framework

There are two types of definitions used in research reports: conceptual and operational. One must define those terms to understand the concepts related to a high quality research report. Conceptual is fact driven and operational is traits, physical components and step by step process. The research in regards to perinatal hospice will be both conceptual and operational. The general idea behind the construction of a conceptual framework is to highlight the coping mechanisms of the grief process. It is defined as a concept by the way others make decisions in a difficult time or situation. For example, what type of action to take when making the decision to continue a pregnancy that you

know will end in broken hearts. However, research has shown that families do desire time with their child. Operational level is the physical elements that have taken hold for families. For example, the ability to be in control of their child's birth and death, therefore beginning the steps of grieving. The populations (control variables) are the families of unborn babies that have been diagnosed with a lethal abnormality. There is a direct relationship between families and the use of perinatal hospice in regards to benefits of having time, however the research does not show a relationship between the perinatal hospices and coping mechanism. Research does show that perinatal hospice was a comfort to those families that had the opportunity to utilize the service.

Significance to Nursing

A perinatal hospice approach supports these families on their journey through pregnancy, birth and death, honoring the baby as well as the baby's family. Perinatal hospice is not a place; it is more a frame of mind. Even in areas without a formal program, parents can create a loving experience for themselves and their baby. Health professionals, family and friends can also offer support in the spirit of hospice. In keeping with hospice ideals, open communication with patients and their families, and all physicians, nurses and support personnel, is essential to prevent problems in even the most carefully crafted plans.

Compassionate listening is the most important goal of the program – to help parents understand that they are not alone and will not be abandoned during this difficult time. Giving hope uses a multidisciplinary team approach that includes obstetricians, perinatologists, labor and delivery nurses, neonatologists, neonatal intensive care unit

staff, chaplains and pastors, social workers, genetic counselors, therapists and traditional hospice professionals. Services include assistance in creating a plan of care and birth plan, resources for spiritual and religious support, creating memories using photographs and mementos, arranging home hospice care, and support groups for parents after their babies have passed away.

The availability of a structured program providing ongoing, comprehensive, multidisciplinary, supportive perinatal care offers a tangible and safe alternative to early elective pregnancy termination for parents carrying a fetus with a lethal congenital condition (Calhoun, Napolitano, Terry, Bussey, & Hoeldtke, 2003).

Chapter II

Literature Review

Perinatal hospice was born out of great sorrow for many families wanting to keep their child alive and to protect them from great pain. Perinatal hospice is a choice parents can make in regards to their child's well being (Kuebelbeck, 2003). Choosing to allow their child to have life in utero and whatever time that is given to them after delivery. The benefit of this choice is to provide parents an opportunity to have memories. While performing a Cumulative Index to Nursing and Allied Health Literature search using scholarly, peer reviewed articles and narrowing down to current information for the last five years, there was limited research available. The purpose of this study is to see if parents that chose perinatal hospice are able to cope more efficiently with their grieving process. More research is needed, therefore; the goal of this researcher is to conduct a quantitative study to generate more knowledge in this area. The following four literature reviews attempt to demonstrate and support the hypothesis.

In a case study by Ramer-Chrastek & Thygeson (2005), a couple became pregnant after attempting for some time, just to find that their unborn child suffered from severe congenital anomalies. The couple consulted several specialists to verify the diagnosis in an attempt to have a more positive outcome. They were advised to abort the pregnancy and try again but this wasn't an option for them because of their religious beliefs. After being informed of a perinatal hospice program at a children's hospital they received a referral to the Deeya Perinatal Hospice program. It was hypothesized in this

study that families prefer more choice options than termination, and prefer the use of a multidisciplinary approach to facilitate the care of their unborn baby. In this case study, the family was able to consult with physicians, nurses, counselors, social workers, chaplains and others for support throughout the pregnancy, birth, and death of their baby. This family was stated as being unique because they were able to benefit from all the aspects of the program (Ramer-Chrastek & Thygeson, 2005).

This case study does not show if by using perinatal hospice that the family was able to better cope with their impending loss, or how quickly they returned to their normal everyday functions. In this study the family had various means of support available to them and they were able to spend some time with their newborn during the child's last moments.

A cross-sectional, descriptive study was conducted by (Engler et al., 2004) to describe neonatal nurse's perceptions of bereavement/end-of-life care of families of critically ill and/or dying infants. The final sample consisted of 1133 hospitals. The sample consisted of eight equally populated regions. A stratified random sample was selected, and a random sample of 30 hospitals was picked from each region; therefore having a final sample of 240 hospitals. The research was conducted by using two questionnaires per hospital, thus having a total of 480 questionnaires. The instrument used was a 55-item survey which was developed by Hickey and Lewandowski that is called the Bereavement/End-of –life Attitudes about Care: Neonatal Nurses Scales (BEACONNS), Comfort Scale, Roles Scale, and Involvement Scale. Completion of those surveys was performed anonymously and the survey constituted a voluntary informed consent. A packet consisting of a cover letter, two copies of BEACONNS, and

a self-addressed, stamped return envelope was mailed to each hospital neonatal intensive care unit nurse manager, which had been randomly selected. To obtain the most actual information the nurse manager was asked to invite the registered nurse and the advanced practice nurse who had the most knowledge in regards to this type of care. The families of the critically ill/ or dying infants families completed the BEACONNS. Result was a response rate of 52% (190 data sets from 125 hospitals out of 240). The conclusion was that education on bereavement/end-of-life care could affect all parties including everyone from the nurse who is caring for the family and or infant to the family and extended family. Additional education on cultural competence would be helpful. They also concluded that nursing curricula should have bereavement/end-of-life content.

Tibballs, & Cantwell-Bartl (2008) did a retrospective review of medical records of infants admitted to the hospital from 1983-2004 with a diagnosis of hypoplastic left heart syndrome in regards to the prenatal diagnosis choice of treatment that was offered to the parents of infants with HLHS. A total of 201 infants from 1983 to 2004 were diagnosed by echocardiography after birth. Among the infants managed non-surgically, compassionate care was chosen by parents, 72 infants were included in this population. In this study approximately half of the parents chose compassionate care for their infant that was diagnosis post-natal, however the parents that received the diagnosis in prenatal stage chose surgical management for their infant. The conclusion was that parents need to have had prenatal screenings to be able to make informed decision in regards to their unborn babies and their outcomes (Tibballs & Cantwell-Bartl, 2008).

A study to test several formats of end-of-life comfort instruments for patients and closely involved caregivers was performed by Novak, Kolcaba, Steiner, & Dowd

(2001). Kolcaba's Comfort Theory was the theoretical framework that was utilized. A total of 38 patient-caregiver dyads were recruited from two hospice agencies. Cronbach's alpha for the end of life comfort questionnaire consisting of a six response Likert-type format was used during the first phase of this study and proved useful for assessing comfort in both the patient and caregiver. Phase two of the study used a four response Likert-type format. The instruments used in this study were based on a definition of comfort that states "the the immediate experience of being strengthened by having the needs for three types of comfort (relief, ease, or renewal) met in four contexts of human experience (physical, psychospiritual, environmental, and social)" (Novak et al. 2001, p 171). The instruments used in this study proved to be efficient, reliable, and useful for assessing comfort in the actively dying patient and their caregivers.

The literature reviews have not provided the back ground material; the researcher needs to support the research. The lack of scholarly research in the area of perinatal hospice and how and if it has helped parents deal with the grief process efficiently has left more unanswered questions than answered questions. Evidence is needed to support the relevance of this type of service on bereavement outcome.

CHAPTER III

Methodology

The purpose of the proposed study is to examine the grief and coping mechanisms in the loss of an unborn child with the aid of perinatal hospice. Recruitment of participants for the proposed study was women who received a diagnosis of a lethal anomaly not compatible with life and used perinatal hospice as a resource to continue their pregnancies. The proposed study will identify choice options for parents who have received a diagnosis of anomalies, and/or fetal death. This study will also evaluate the parents' grief process and coping mechanism. Findings from this proposed study may help in providing perinatal hospice to unborn babies and their families by giving them time to parent their child and cope with the impending loss.

Prior to conducting the research, the researcher obtained permission from the Internal Review Board (IRB) from Gardner-Webb University (Appendix B). Once approval was obtained, each participant was given a copy of an informal cover letter (Appendix A) attached to the three survey questionnaire, a demographic data form as well as a program evaluation. The consent form ensured a voluntary nature of the participants, opportunity to withdraw at any time, and agreement to the one-time completion of a questionnaire requiring less than thirty minutes to complete. The return of the questionnaire was considered to be implied consent of participation. Confidentiality was ensured and all returned surveys were anonymous. Participants were asked to refrain from putting any identifying marks on the questionnaire. The

recruitment for participants was accomplished by contacting a Perinatal Hospice Network to allow the researcher to mail out questionnaires to their clients for participation in this quantitative study. Perinatal Hospice Network contacted the clients that had used perinatal hospice and had suffered a loss more than twelve months ago. After receiving verbal consent from the participants the researcher was given a list of addresses. The participants were then mailed the data to be completed. A stamped addressed envelope was also included for the participants to return all data. The participants were not offered any money, preferential treatment, or gifts for participating with this research study.

Method

A descriptive design was used in this study to determine how well families coped while being involved with the perinatal hospice program. The focus will be to obtain feedback from families who have had a diagnosis of fetal anomalies or fetal death. A questionnaire was mailed to the participants for basic demographic information and program evaluation, as well as three surveys: Holistic Comfort Questionnaire, Comfort with End of Life Planning created by Dr. Kathy Kolcabe, 2003, and Core Bereavement Items created by Professor Paul C. Burnett, 1997. Questions were related to the client's personal experiences with the hospice program in which they were involved. Did it fulfill their needs and expectations? To help decrease the threat to this research, the questionnaire was given to participants with a stamped addressed envelope with information as not to reveal their identities.

Three main types of surveys used a Likert scale ranging from a zero to five measurements. The participants' had to score questions from strongly disagree (1) to strongly agree (5) on both the Holistic Comfort Questionnaire (HCQ) and the Comfort

with End of Life Planning (CELP). Core Bereavement Item (CBI) survey questions related the participants experiences in the loss of their child on a scale of three (continuously) or zero (never).

The Holistic Comfort Questionnaire (HCQ) assessment was used to measure the comfort that the families received while dealing with the loss of their unborn child. The HCQ is a survey that contains 49 statements. The statements pertain to the comfort that the families received during their hospital stay. The client questionnaire had a 5-item Likert scale response set; ranging from “strongly agree” to “strongly disagree”, the higher scores indicated a higher comfort. Each questionnaire should have taken about 10 minutes for the client to complete. Five numbers were provided for each question. The participants had to circle the one that most matched their feelings. Total comfort lines were oriented vertically and consisted of the stem: “I am as comfortable as I can be right now,” Participants were asked to circle the line corresponding to how they felt at the moment the care was being performed (Novak, Kolcaba, Steiner & Dowd, 2001).

The Comfort with End of Life Planning (CELP) assessment was used to measure the comfort that families received while dealing with the loss of their unborn child. The CELP is a survey that contains 28 statements. The statements pertain to the comfort that the families received during their hospital stay. The client questionnaire had a 5-item Likert scale response set; ranging from “strongly agree” to “strongly disagree”, the higher scores indicated a higher comfort. Each questionnaire should have taken about 10 minutes for the client to complete. Five numbers were provided for each question. The participants had to circle the one that most matches their feelings. Total comfort lines were oriented vertically and consisted of the stem: “I am... right now.” Participants were

asked to circle the line corresponding to how they felt at the moment the care was being performed.

The Core Bereavement Items (CBI) assessment was used to measure the how the client related to their loss of a loved one. The CBI is a survey that contains 17 statements. The statements pertain to the experience that the families had and how their loss related to others. The survey consist of a four statement response set; “a lot of the time (three)” to “never (zero)”, the higher scores on this scale indicates more bereavement-related symptomatology, which would indicate the families are continuously or at least a lot of the time still thinking about their loved one that they had lost. Participants were asked to mark the responses that best fixed their experience in relation to the recent loss of their child. The CBI consisted of the stem: “Do you...or...Are you reminded...”

The approval to modify the tools (Appendix D) was obtained and the content of the tools were adapted from existing survey to assess the experience of the families with respect of end of life care for their unborn child.

The Holistic Comfort Questionnaire (HCI), Comfort with End of Life Planning (CLEP) and Core Bereavement Items (CBI) measurement tools have been used in numerous settings and have proven to be effective tools in regards to measuring comfort, planning, and bereavement concerns. The sample method used for this quantitative research was a clinical database for support networks. The sampling procedure used by the researcher was convenience sampling. The participants were restricted to those that had already used hospice services. There were nine participants in this study. The

purpose will be explained to them by mail. The purpose of this study was to gather information to determine if families facing the impending loss of a child felt that perinatal hospice facilitated the grieving process. The researcher developed a demographic information tool which reported the participant's gender, age, education level, ethnicity, employment, marital status, and at what gestational age they received their babies diagnosis, and what options were given to them (Appendix E).

A purposive sampling will be used to gain insight into a new area of study or to explain coping mechanism of families that are dealing with loss of their unborn baby at delivery or thereafter.

At any time during the study the participants could decline to participate in the study without question. The cover letter (Appendix A) provided the participant with contact numbers of the primary investigator (PI) and the Internal Review Boards at Gardner-Webb University. The detailed cover letter provided information concerning the benefits and risk of the study.

Ethics

Following the study's approval by Gardner-Webb University Research Review Board (Appendix B), the questionnaires were mailed out by the researcher. Participants were asked to return the survey via postal mail within two weeks. The results of all tools were analyzed utilizing Statistical Package for the Social Sciences (SPSS 18th).

There is no instrument that has been developed to measure how perinatal hospice has helped families use their coping mechanism or to evaluate parent's grief process. All the results will be compared, sorted and summarized. The data will go through the process that is appropriate for research: validation and reliability.

Grief is a very lonely process. Everyone must work through this in their own way; however caregivers can provide care for the dying child and their families in a systemic way that will bring them comfort and support. By viewing families who have chosen perinatal hospice caregivers can improve patient care, coping mechanisms, and as a result, have opportunities to integrate perinatal hospice into a comprehensive care facility and as a result giving families more choices.

Chapter IV

Results

Sample

The target population reflected specific characteristics and were accessible for this study. The participant's were all female ranging in ages from 20 to 37 years old. All participants had completed either a GED (n=2), high school diploma (n=1), and/or a four year college degree (n=6). All nine participants were married / partnered. The ethnicity of this population was one African American and eight Caucasians. All participants had unborn babies that had a fetal diagnosis that was not compatible with life and were diagnosed between 13 and 22 weeks of gestation. Each participant's loss had occurred over a one year time span prior to this study. The options given to each participant at diagnosis were as follows: perinatal hospice referral (n= 1), terminate (n=1), other (n=1) or a combination of options (n=7): the options included a combination of perinatal hospice, terminate and or carry the baby to term without perinatal hospice

Instruments

The first instruments: Holistic Comfort Questionnaire (HCQ) and Comfort with End of Life Planning (CELP) are tools that assess quality of comfort using a general questionnaire. The HCQ and CELP questionnaires were given to the participants and measured the extent to which the responder was experiencing comfort and care at the time of care. Both HCQ and CELP are Likert type scales based on how often the participants agreed or disagreed with the statements. Each item is presented as a statement such as these from the HCQ, "We made the right decision when we chose hospice" or "There are those I can depend on when I need help" or "I like my room to be

still and quiet” or “When the situation was over, it has been difficult to resume my former responsibilities”. Some examples of CELP statements include, “Perinatal Hospice helped me to get information about end of life care for my baby” or “I felt confident with the support I received” or “My condition got me down” or “I didn’t want to think about making plans for my baby’s death”. The survey measured basic needs for comfort during the grieving process and making end of life choices. Participants scored each statement on a five point Likert type scale based on what they felt matched their feelings at the time of their baby’s death or hospital stay. The participants choices were strongly disagree, disagree, neutral, agree, or strongly agree. The primary measured domain was outcome and the secondary measured domain was patient experience (Kolcaba 2000; Steiner, 2000). Variables that were assessed dealt with items such as patient comfort for pain, anxiety, loneliness, sadness and guilt and how they reacted to their experience. Each tool had negative and positive statements that the participants had to rate on a score from one to five.

The second instrument was the Core Beavrent Item (CBI). This 17-item tool measured normal grief (Neimeyer & Hogan, 2001, for review). CBI focused on the personal, cognitive, and emotional elements of grief currently experienced by the bereaved. Each item was presented as a question, such as “Do you find yourself preoccupied with images or memories of _____?” or “Do you find yourself thinking of a reunion with _____?”. Responses are given on a four point Likert type scale based on how often the participants experience that item. Participants may choose: never, a little bit of the time, quite a bit of the time, or always. Participants are scored zero, one, two, or three, respectively, with the overall score being determined by the sum of individual

items, ranging from zero to fifty-one. The scale's author reports high internal consistency ($\alpha=.92$) with a sample of 158 bereaved adults (Burnett et. al., 1997). The author also found evidence for construct validity in that the CBI discriminated between different subsets of the bereaved based on varying levels of grief intensity. There are three components that were also analyzed including images and thoughts, acute separation, and grief. Subsequent testing of the tool had also confirmed the reliability and validity of the instrument (Kristjanson, Cousin, Smith, & Lewin, 2005).

Other variables

Basic demographic information was gathered for each participant, including age, sex, ethnicity, educational background, marital status and gestation when diagnosis was obtained. Nine participants completed a one-time battery of instruments that included demographic items, program evaluation, the Holistic Comfort Questionnaire (HCQ), the Comfort with End of Life of Planning (CELP) and Core Bereavement Items (CBI) survey. Sixty percent of the 15 questionnaires that were mailed out were returned. One hundred percent of the nine returned questionnaires were by females. The participants ranged from 20 to 37 years of age with a median age of 29 and a standard deviation of 5.809. The ethnicity of the participants was noted as one African American and eight Caucasians. One hundred percent of the participants were employed. Eight of the participants had completed a college degree while two had completed a GED. The gestational age of the participant's unborn babies at the time of the diagnosis of abnormality ranged from 13 to 22 weeks with a mean of 19 and a standard deviation of 2.55. The choices offered at the time of the diagnosis varied, with seven of the participants having multiple choices and two receiving only a single option. The options

offered to the participants ranged from 88.8 percent receiving the option of hospice, 77.7 percent to terminate, 11.1 percent to carry to term without hospice (Table 1).

Table 1

Summary of Demographic Data of Participants

Characteristic	Frequency	Percent	M	SD
	0	0	0	0
Gender				
Male	0			
Female	9	100%	29.00	5.809
Education				
GED	2	22.2%		
High School	1	11.1%		
College	6	66.7%	3.11	1.364
Ethnicity				
Caucasian	8	88.9%		
African American	1	11.1%	3.11	1.364
Marital Status				
Married/partnered	9	100%	29.00	5.809
Employment				
Full Time	6	66.7%		
Unemployed	4	43.3%		
Gestation Age of Baby				
13 weeks	1	11.1%		
18 weeks	1	11.1%		
20 weeks	7	77.8%	19.00	2.550
Options				
Prenatal Hospice	1	11.1%		
Terminate	1	11.1%		
Both	6	66.7%		
Other	1	11.1%	19.00	2.550

Each participant was asked to complete an evaluation of the program that they used. There were seven statements that dealt with the program's effectiveness. The participants were instructed to circle the number on the scale from one (not effective) through five (highly effective) that best represented how they felt in regards to the program and the services provided to them. The program evaluation was divided up into two sections. The first section had four general statements in regards to the importance of communication with the interdisciplinary team, factors that influence communication in the hospice setting, describing the importance of factors in communicating bad news and characteristics of what the patient/family expected of the professional caring for them in the hospital setting. The second section was an overall program evaluation. It dealt with subjects related to the usefulness of content to clinical practice, timeframe of meeting with staff and effectiveness as a learning event.

The program evaluation also looked at the goals, processes, inputs, outputs and the impact of the program. This program showed that 100% of the participants responded to the evaluation. The possible scores for the program evaluation were one through thirty-five. The mean score was 34.5556, which is a positive indicator that the participants agreed with the program and the outcome for them was an encouraging experience.

(Table 2)

Table 2 part A

Summary Program Evaluation

Using a scale of 1 (not effective) through 5 (highly effective), the participants related how effective perinatal hospice had been to enable them to meet their desired outcomes.

Frequency Table

PE1-Define the importance of ongoing communication with the interdisciplinary team, patient, and your family throughout perinatal hospice process.

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 4	1	11.1	11.1	11.1
5	8	88.9	88.9	100.0
Total	9	100.0	100.0	

PE2-Identify factors that influence communication in the hospice setting

PE3-Describe important factors in communicating bad news

PE4-Identify characteristics patient/family expect of healthcare professional in caring for them in the hospital setting

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 3	1	11.1	11.1	11.1
5	7	77.8	77.8	88.9
6	1	11.1	11.1	100.0
Total	9	100	100	

Table 2 Part B

Overall Program Evaluation

Using a scale of 1 (poor) through 5 (excellent), the participants rated the following areas:

PE5- Usefulness of content to clinical practice

PE6 -Timeframe of meeting with staff

PE7- Effectiveness as a learning event

Frequency Table

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 4	1	11.1	11.1	11.1
5	7	77.8	77.8	88.9
6	1	11.1	11.1	100.0
Total	9	100	100	

Descriptive Statistics for the overall program evaluation questionnaire total raw score
(Point Scale 1-5: possible range 7-35)

	N	Minimum	Maximum	Mean	Std. Deviation
SumPE	9	28.00	41.00	34.5556	3.39526
N	9				

These statistics were reassuring to the perinatal hospice program

All clients were asked to complete the HCQ, CELP and CBI survey (appendix D). The HCQ and the CELP survey had positive and negative statements which the participants had to score from one which equaled “strongly disagree” to five that represents “strongly agree”. The CBI was scored based on 17-item statements that ranged from three to zero. “A little bit of the time” equaled one, “Never” would equal a zero score. The CBI has three subset scores already incorporated into the tool: the subsets were Images and Thought, and Acute Separation and Grief.

The Holistic Comfort Questionnaire (HCQ)

The total possible range of scores range for the HCQ was 49 to 245. Each statement was scored in the range from one-strongly disagree to five-strongly agree. The statements therefore can be viewed as being from one-negative to five-positive. Some negative statements were intentionally inserted into the HCQ in order to prevent and determine if someone had simply selected all of the positive or negative Responses. These negative statements were then reversed to the positive when scoring the HCQ. Therefore a score of 245 would indicate all responses were positive or in complete agreement, and a score of 49 would indicate all responses were negative or in complete disagreement. The mean score for the HCI was 185. This would indicate 75.5 percent of the responses were in the positive or in agreement with the questionnaire. On a per statement level with a range of one to five the mean was 3.79. Using this figure there are some statements that are more revealing than others. In looking at the five highest scoring statements, statement 18 had a mean of five. This statement read “we made the right decision when we chose hospice”, as the answers reveal all were in complete agreement with this

statement. Statement three had a mean of 4.78. This statement read “there are those I can depend on when I need help”. Statement 21 had a mean of 4.78. This statement read “I had a special person(s) who made me feel cared for”. Statement seven read “my life is not worth living”. When the researcher reversed this negative statement it had a mean of 4.67. Statement 8 had a mean of 4.67. This statement read “I know that I am loved and my baby was loved. The five statements that scored the lowest were: statement four which read “I worry about others in my family”. When the researcher reversed this negative statement it had a mean of 2.11 showing great concern for others. Statement 46 had a mean of 2.22 and read “I think about the future a lot”. Statement 29 when reversed had a mean of 2.44 and read “I wanted my family to be more comfortable. Statement 26 when reversed had a mean of 2.78 and reads “when the situation was over it has been difficult to resume my former responsibilities”. Statement 37 when reversed had a mean of 2.78 and read “I feel helpless. In looking at these answers one can see that hospice was a valuable tool for these parents. Parents felt good about their decision to use hospice and felt loved and cared for. They were more concerned for others or other things than themselves. (Table 3)

Table 3

Holistic Comfort Questionnaire

Using a scale of 1 (strongly disagree) through 5 (strongly agree). The participants were asked to circle the number their though closely matched their feelings at the moment of care.

Descriptive Statistics for the HCQ questionnaire total raw score

(Point Scale 1-5: possible range 49- 245)	N	Minimum	Maximum	Mean	Std. Deviation
sumHOLISTIC Valid N	9 9	159.00	222.00	185.6667	17.61391

	N	Minimum	Maximum	Mean	Std. Deviation
meanHOLISTIC Valid N	9 9	3.24	4.53	3.7891	.35947

Comfort with End of Life Planning

The total possible score range for the CELP was 28 to 140. Each statement was scored in the range from one-strongly disagree to five-strongly agree. The statements therefore can be viewed as being from one-negative to five-positive. Some negative statements were intentionally inserted into the CELP in order to prevent and determine if someone had simply selected all of the positive or negative answers. These negative statements were then reversed to the positive when scoring the CELP. Therefore a score of 140 would indicate all responses were positive or in complete agreement, and a score of 28 would indicate all responses were negative or in complete disagreement. The mean score for the CELP was 104.8. This would indicate 74.9 percent of the responses were in the positive or in agreement with the questionnaire. On a per statement level with a range of one to five the mean was 3.75. Using this figure there are some statements that are more revealing because of their high or low scores. These were the five highest scoring. Statement 25 had a mean of five and read "I feel my life is worthwhile now". Statement four had a mean of 4.67 and read "I felt confident with the support I received". Statement one had a mean of 4.56 and read "there were those I could depend on when I need help". Statement five had a mean of 4.56 and read "I feel my life is worthwhile right now". Statement 28 had a mean of 4.56 and read "I have found meaning in my baby's life and death". These are the five lowest scoring statements. Statement three had a mean of 1.56 after being reversed and read "my condition got me down". Statement 15 read "I am still afraid of what will happen in the future" and had a mean of 2.22 after being reversed. Statement 16 had a mean of 2.22 after being reversed and read "I am tired". Statement 21 had a mean of 2.78 after being reversed and read "I have experienced changes that make

me feel uneasy”. Statement 14 had a mean of 3.11 and read “birthing planning made me feel scared”. From these answers the researcher could see that the participants felt good about their comfort level, the choices they made, and the help they received. The researcher could also see that they were tired and apprehensive about the changes they have experienced and may experience. (Table 4)

Table 4

Comfort with End of Life Planning

Using a scale of 1 (strongly disagree) through 5 (strongly agree). The participants were asked to circle the number they thought closely matched their feelings at the moment of care.

Descriptive Statistics for the CELP questionnaire total raw score
(Point Scale 1-5: possible range 28-140)

	N	Minimum	Maximum	Mean	Std. Deviation
sumCOMFORT	9	86.00	129.00	104.8889	11.38469
Valid N	9				

	N	Minimum	Maximum	Mean	Std. Deviation
meanComfort	9	3.07	4.61	3.7460	.40660
Valid N	9				

Table 6

Mean and Standard Deviation for Questionnaire Scores

Questionnaire	M	SD
Holistic Comfort	185.66	17.61
Comfort with End of Life Planning	104.88	11.38
Core Bereavement	24.37	8.53
Core Bereavement Subsets:		
Images and Thoughts	10.50	3.50
Acute Separation	7.62	2.66
Grief	6.25	4.02

Chapter V

Discussion

Interpretation of Findings

The purpose of this study was to determine if perinatal hospice helped facilitate families with the grieving process and their coping mechanisms. Because of the limitations of the method in data collection – survey sent out to the participants in only perinatal hospice- the findings cannot be generalized to all bereaved parents. In addition, the participants were all female, mostly white, and educated. The questionnaire method allowed the researcher to survey a small group of parents but did not offer the opportunity for follow up. The study did not consider factors that may have affected the process, such as the lethal anomalies, if the baby was born alive or had already passed away, and if the baby was born alive how long did the baby survive.

In spite of these limitations, the information gathered in the study offers a look at the grief experience of the families that were able to utilize perinatal hospice. The results of this study indicated that there was a significant relationship between the perinatal hospice and the participant's satisfaction with care (Table 2).

The program evaluation used a scale of one which was “not effective” through five which was “highly effective”. The participants were asked to circle one of the four objectives that best represented them and their satisfaction. They were also asked to evaluate the overall program using 1 as poor to 5 as excellent. All participants (n=9) in the study reported satisfaction in the hospice program. The sum of the program evaluation is 34.5556 with a STD of 3.39.

The study had a number of limitations. First, the study took place in a free sitting perinatal hospice environment, and it had limited representation of ethnic groups and cultures.

For some parents keeping the memory of the baby alive was a way to make meaning of the death. It is important that this focus on the baby is viewed as a way of making sense of the diagnosis in order to reinvest in the world, not an attempt to deny the reality of the death. In making meaning of the death the parents have to find meaning in their ongoing lives. The greatest majority of the participants in the study could identify meaning in their lives. Contact with people was strongly agreed with in the study and knowing that they made the right decision when they chose hospice rather than other options that had been given to them.

Implications' for Nursing

The findings of this study indicate that caregivers had a positive impact on the families in the study. Families need to share with others the events and feelings surrounding the death of their babies. The bereaved remember and retell every detail, over and over. This is a way that they can validate that their child existed. They need to tell their story even if it just by performing a survey.

The Comfort Theory is guided by the theoretical principles that espouse the human. The nurse who is guided by this theory will look beyond what she sees

Implications for Further Research

Recommendations for further research includes a comparative randomized study utilizing clients after diagnosis is given and what choices were given to them. Further research might also include an increased sample size and a more diverse population.

Additional research on effects of the family's dynamics will need to be carefully defined and measured to yield an accurate understanding of the effects of perinatal hospice and the ways in which it promotes a positive health outcome.

Comfort instruments are relevant to the experience of active dying, and are more congruent with the goals of care of the unborn dying child. Comfort is a concept that is easily understood by patients, all of whom want the interdisciplinary team to make them as comfortable as possible. The participants responded strongly to all the questionnaires in regards to comfort and holistic care. This speaks to the internal validity of the instruments.

These instruments have good psychometric properties, meeting criteria of efficiency, sensitivity, reliability, and beginning validity for new measures in this area (Cohen & Mount, 1992).

Limitations

The results of the study are limited by the single setting and lack of random sampling. There is a possibility that there are individuals that would not have chosen hospice care from a different setting or different geographic area. Characteristics such as age, gender, ethnicity, and education may or may not have played a role in the data received. Another limitation is the small sample size. The results of this study may not be generalized to other samples that do not meet same characteristics.

Conclusions

Families who are informed before the birth about anomalies and/or medical conditions can plan for the care of their child. Change has occurred in the pattern of providing care for this population of infants with lethal anomalies, which brings the end

of life in such proximity to its beginning and end (Hoeldtke& Calhoun, 2001). Hospice care in this population has become increasingly popular and though this is a sad time for both the caregiver and the family this type of care is needed for babies and their families. This research study showed that families found comfort and closure in knowing that they have done everything that they could possible do for their children and their families well being.

Perinatal hospice is care that relieves symptoms and suffering but does not cure; it is at the core of palliative care and is seen in a high contrast to the critical care provided to the sick neonate. As a means to effectively support the family experiencing perinatal loss, clinicians work outside the familiar and comfortable action-oriented role (Leuthner, Boldt & Kirby, 2004).

Comforting words and actions by the nurse and other members of the health care team as well as the intent to comfort are important for interventions to be perceived as comforting a measure (Kolcaba, 2003). Many have defined comfort in various ways. From this research, the researcher can conclude that comfort would be family around with smiles on their faces and a love that binds them together even in the toughest of times. A simple kiss on ones cheek and words of affection and love whispered. Thus with the end of life near one can slip from this world to the next knowing that they were care for.

Since the start of this study the researcher has had many thoughts of those parents that complete those simple surveys; and the great courage it must have taken for them to choose to continue their pregnancy even though they knew it would end.

American Psychological Association (2009). *Publication manual of the American Psychological Association* (6th ed). Washington, DC: Author.

Attign, T. (2000). *The heart of grief*. New York: Oxford.

Burnett, P., Middleton, W., Raphael, B., & Martinek, N. (1997). Measuring core bereavement phenomena. *Psychological Medicine*, 27(1), 49-57.

Calhoun, BC., & Hoeldtke, NJ. (2000). The perinatal hospice: Ploughing the field of natal sorrow. *Frontiers in fetal health*. (5).

Calhoun, BC., Napolitano, P., Terry, M., Bussey, C., & Hoeldtke, NJ. (2003). Comprehensive care for the family of the fetus with lethal condition. *The Journal of Reproductive Medicine*, 48, 343-348.

Chescheir, NC., & Cefalo, RC. (1992). Perinatal diagnosis and caring. *Women's Health Issues*, 2, 123-132.

Cohen, S., Mount, B. (1992). Quality of life in terminal illness: defining and measuring subjective well-being in the dying. *Journal of Palliative Care*. 8(3), 40-45.

Engler, AJ., Cusson, RM., Brockett, RT., Cannon-Heinrich, CC., Goldberg, MA., Gorzkowski West, M., & Petow W. (2004). Neonatal staff and advanced practice nurses' perceptions of bereavement/end-of-life care of families of critically ill and/or dying infants. *American Association of Critical-Care Nurses*, (13), 489-498.

- Hoeldtke, NJ., & Calhoun, BC. (2001). Perinatal hospice. *American Journal of Obstetrics and Gynecology.*, 3, 525-529.
- Klass, D. (1999). Assumptive worlds and the stress of traumatic events. *Social Cognition*, 7, 113-116.
- Klass, D. Silverman, PD., & Nickman, S. (1996). *Continuing bonds: New understandings of grief*. Washington: Taylor & Francis.
- Kolcaba, K. (2003). *Comfort theory and practice: a vision for holistic health care and research*. New York, NY: Springer Publishing Company.
- Kristjanson, LJ., Cousin, K., Smith, J., & Lewin, G. (2005). Evaluation of the bereavement risk index (BRI): a community hospice care protocol. *International Journal of Palliative Nursing*. 11(12), 610, 612-618.
- Kübler-Ross, E. (1986). Some babies die: An exploration of stillbirth and neonatal death, video. *University of California extension media*.
- Kuebelbeck, G. (2003). *Waiting with Gabriel*. Chicago, Ill.: Loyola Press
- Leuthner, SR., Boldt, AM., & Kirby, RS. (2004). Where infants die: examination of places of death and hospice/home healthcare options in the state of Wisconsin. *Journal of Palliative Medicine*, 7(2), 269-77.
- Limbo, R., Toce, S. & Peck, T. (2008/2009). Resolve through sharing position paper on perinatal palliative care. La Crosse, WI: Gundersen Lutheran Medical Foundation, Inc. <http://www.bereavementservices.org>.

- Powers, D. (2006). Perinatal hospice: another choice for women facing unplanned pregnancies? *Conscience*.
- Novak, B., Kolcaba, K., Steiner, R., & Dowd, T. (2001). Measuring comfort in caregivers and patients during late end-of-life care. *American Journal of Hospice & Palliative Care*, 18 (3, May/June). 170-180
- Ramer-Chrastek, J., & Thygeson, M. (2005). A Perinatal hospice for an unborn child with a life-limiting condition. *International Journal of Palliative Nursing*, II(6), 274-277.
- Rubin, SS. (1985). Maternal attachment and child death: on adjustment, relationship, and resolution. *Omega*, 15, 347-353.
- Saunders, C., *Beyond the Horizon*. London: Darton, Longman and Todd
- Tibballs, J., & Cantwell-Bartl, A. (2008). Outcomes of management decisions by parents for their infants with hypoplastic left heart syndrome born with and without a prenatal diagnosis. *Journal of Paediatrics and Child Health*, (44), 321-324.
- Urdang, L. (Ed.). 1968. *The Random House Dictionary of the English Language*. New York: Random House.

Appendix A

Cover Letter/Informed Consent

APPENDIX A

Dear Participates,

My name is Sally Smith and I am a labor and delivery nurse, and a graduate student working on my master in nursing education at Gardner-Webb University, Boiling Springs, North Carolina.

I am conducting research to investigate the effectiveness of Perinatal Hospice in the grieving process and coping mechanism.

Enclosed is survey that will measure certain indicators for my research. Your participation is voluntary and the survey should take approximately thirty minutes to complete. By completing and returning the survey, informed consent is given. Please do not include your name or any markings that could identify you on the returned survey.

There is no compensation for your participation in the study and there are no known benefits or risks for completion of the survey. All data will remain confidential, and if the study is published, no individual data or the site of collection will be identified. Contact information is listed below. Feel free to contact me or my thesis advisor at any time regarding questions that you might have relating to the research. I appreciate your time and efforts in helping to make my research a success.

Thank you for your consent and assistance with this study. If you have any questions please feel free to contact me by phone 864-978-5781 or by e-mail sixsmiths6@charter.net or regular mail at 171 Miles Dr. Spartanburg, SC 29306. My thesis advisor is Dr. V. Walker you may contact her at P.O. Box 7268 Boiling Springs, NC 28017 or vwalker@gardner-webb.edu.

Sincerely,

Sally Smith RN, BSN

Gardner-Webb University

Appendix B
Gardner-Webb University
Institutional Review Board (IRB)



THE INSTITUTIONAL REVIEW BOARD
of
GARDNER-WEBB UNIVERSITY

This is to certify that the research project titled

Holistic Comfort and Bereavement of Families receiving Prenatal Hospice support during the loss of an unborn child with lethal anomalies

being conducted by Sally Smith

has received approval by the Gardner-Webb University IRB.

Date 6/13/11

Exempt Research

Signed [Signature]

Department/School/Program IRB Representative

[Signature]

Department/School/Program IRB Member

Expedited Research

Signed _____
Department/School/Program IRB Representative

Department/School/Program IRB Member

IRB Administrator or Chair or Institutional Officer

Non-Exempt (Full Review)

Signed _____
IRB Administrator

IRB Chair

IRB Institutional Officer

Expiration date 6-13-11

IRB Approval:

Exempt Expedited Non-Exempt (Full Review)

Revised 09-09

Appendix C
Agency Approval



PO Box 5673, Greenville, SC 29606
864.423.3708

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www.perinatalsupport.com

June 11, 2011

To Whom It May Concern: Sally Smith, RN, graduate nursing student at Gardner-Webb University has requested permission to send out a survey to a random selection of families who have participated in our perinatal hospice program for research related to her master's thesis. I have spoken with and have received permission from each family who will take part in this research project. Each of them seems to appreciate the opportunity to share their experience. They have been assured of their confidentiality.

If you have any questions or concerns, please feel free to call me.

A handwritten signature in cursive script that reads 'Tammy Tate'.

Tammy Tate, CEO

Carolina Perinatal Support Network
864-419-4519

Appendix D

Tools

Appendix D-1

SCALES: CORE BEREAVEMENT ITEMS (CBI)

These questions are about your experience in relation to the recent loss of your loved one, whose name in these questions will be signified by the symbol X.

1. Do you experience images of the events surrounding X's death?
 Continuously Quite a bit of the time A little bit of the time Never
2. Do thoughts of X's come into your mind whether you wish it or not?
 Continuously Quite a bit of the time A little bit of the time Never
3. Do thoughts of X make you feel distressed?
 Always Quite a bit of the time A little bit of the time Never
4. Do you think about X?
 Continuously Quite a bit of the time A little bit of the time Never
5. Do images of X make you feel distressed?
 Always Quite a bit of the time A little bit of the time Never
6. Do you find yourself preoccupied with images or memories of X?
 Continuously Quite a bit of the time A little bit of the time Never
7. Do you find yourself thinking of reunion with X?
 Always Quite a bit of the time A little bit of the time Never
8. Do you find yourself missing X?
 A lot of the time Quite a bit of the time A little bit of the time never
9. Re you reminded by familiar objects (photo, possessions, rooms etc) of X?
 A lot of the time Quite a bit of the time A little bit of the time never
10. Do you find yourself pinning for/yearning for X?
 A lot of the time Quite a bit of the time A little bit of the time never
11. Do you find yourself looking X in familiar places?
 A lot of the time Quite a bit of the time A little bit of the time never

12. Do you feel distress/pain if for any reason you are confronted with the reality that X is not coming back?

___A lot of the time ___Quite a bit of the time ___A little bit of the time ___never

13. Do reminders of X such as photos, situations, music, places etc cause you to feel longing for X?

___A lot of the time ___Quite a bit of the time ___A little bit of the time ___never

14. Do reminders of X such as photo, situations, music, places etc cause you to feel loneliness?

___A lot of the time ___Quite a bit of the time ___A little bit of the time ___never

15. Do reminders of X such as photos, situations, music, places etc cause you to cry about X?

___A lot of the time ___Quite a bit of the time ___A little bit of the time ___never

16. Do reminders of X such as photos, situations, music, places cause you to feel sadness?

___A lot of the time ___Quite a bit of the time ___A little bit of the time ___never

17. Do reminders of X such as photos, situations, music, place etc cause you to feel loss of enjoyment?

___A lot of the time ___Quite a bit of the time ___A little bit of the time ___never

SCORING CRITERIA:

The responses for all items will be scored using the following format:

(3)Continuously (2) Quite a bit of the time (1) A little bit of the time (0) Never

- Items 1 to 17 are added together to form a total score for the CBI
- Items 1 to 7 are added together to form the Images and Thoughts Subscale
- Items 8 to 12 are added together to form the Acute Separation Subscale
- Items 13 to 17 are added together to form the Greif Subscales

Modify by Sally S. Smith RN, BSN with written permission from Professor Paul Burnett: May 22, 2011. Dean of Research and Research Training Queensland University of Technology. <http://p.burnett@qut.edu.au>

Scales: Core Bereavement Items

Burnett, PC., Middleton, W., Raphael, B., & Martinek, N. (1997). Measuring core bereavement phenomena. *Psychological Medicine*, 27, 49-57.

Appendix D (2)

Comfort with End of Life Planning

Thank you VERY MUCH for helping me in this study. Below are statements that may describe your comfort during your grieving process and making end of life choice for your baby. Five numbers are provided for each question: please circle the number you think most closely matches your feeling. This is about you when you were dealing with the choices you had to make for your baby.

=====

1=STRONGLY DISAGREE, 2=DISAGREE, 3=NETURAL, 4=AGREE, 5=STRONGLY AGREE

- | | | | | | |
|--|---|---|---|---|---|
| 1. There were those I could depend on when I needed help | 1 | 2 | 3 | 4 | 5 |
| 2. I didn't want to think about making plans for my baby death | 1 | 2 | 3 | 4 | 5 |
| 3. My condition got me down | 1 | 2 | 3 | 4 | 5 |
| 4. I felt confident with the support I received | 1 | 2 | 3 | 4 | 5 |
| 5. I feel my life is worthwhile right now | 1 | 2 | 3 | 4 | 5 |
| 6. I am inspired by knowing that I am loved | 1 | 2 | 3 | 4 | 5 |
| 7. I trust my doctors to make the right decisions | 1 | 2 | 3 | 4 | 5 |
| 8. No one understood my pain and sorrow | 1 | 2 | 3 | 4 | 5 |
| 9. My anxiety is difficult to endure even now | 1 | 2 | 3 | 4 | 5 |
| 10. I am scared when I am alone | 1 | 2 | 3 | 4 | 5 |
| 11. I am relaxed right now | 1 | 2 | 3 | 4 | 5 |
| 12. I feel agitated right now | 1 | 2 | 3 | 4 | 5 |
| 13. I do not feel healthy right now | 1 | 2 | 3 | 4 | 5 |
| 14. Birthing planning made me feel scared | 1 | 2 | 3 | 4 | 5 |
| 15. I am still afraid of what will happen in the future | 1 | 2 | 3 | 4 | 5 |
| 16. I am tired | 1 | 2 | 3 | 4 | 5 |
| 17. I am content | 1 | 2 | 3 | 4 | 5 |
| 18. I still feel dependent on other to make decision for me | 1 | 2 | 3 | 4 | 5 |

19. My faith helps me to be strong	1	2	3	4	5
20. I feel out of control	1	2	3	4	5
21. I have experienced changes that make me feel uneasy	1	2	3	4	5
22. My family was aware of my wishes for my baby regarding care at the end of his/her life	1	2	3	4	5
23. I need to be better informed about my health choices	1	2	3	4	5
24. I didn't feel like I had many choices	1	2	3	4	5
25. Perinatal Hospice helped me to get information about end of life care for baby	1	2	3	4	5
26. I feel peaceful with my choices	1	2	3	4	5
27. I am depressed	1	2	3	4	5
28. I have found meaning in my baby life and death	1	2	3	4	5

Modify by: Sally Smith RN, BSN with written permission from Dr. Kathy Kolcaba: May 15, 2011. Associate Professor (Emeritus) The University of Akron Adjunct Faculty, Ursuline College <http://www.TheComfortLine.com>

Appendix D (3)

Holistic Comfort Questionnaire

Thank you VERY MUCH for helping me in the study of hospice nursing. Below are statements that pertain to the comfort you and your baby received. Five numbers are provided for each question: please circle the number you think most closely matches your feeling. Relate these questions to your experience at the moment of care.

=====1
 =STRONGLY DISAGREE, 2=DISAGREE, 3=NETURAL, 4=AGREE, 5=STRONGLY AGREE

- | | | | | | |
|--|---|---|---|---|---|
| 1. My body feels relaxed right now | 1 | 2 | 3 | 4 | 5 |
| 2. We did not have enough privacy | 1 | 2 | 3 | 4 | 5 |
| 3. There are those I can depend on when I need help | 1 | 2 | 3 | 4 | 5 |
| 4. I worry about others in my family | 1 | 2 | 3 | 4 | 5 |
| 5. My belief gave me peace of mind | 1 | 2 | 3 | 4 | 5 |
| 6. Our nurse(s) give me hope & support | 1 | 2 | 3 | 4 | 5 |
| 7. My life is not worthwhile right now | 1 | 2 | 3 | 4 | 5 |
| 8. I know that I am loved and my baby was loved | 1 | 2 | 3 | 4 | 5 |
| 9. The surroundings were pleasant | 1 | 2 | 3 | 4 | 5 |
| 10. I had difficulty resting still | 1 | 2 | 3 | 4 | 5 |
| 11. No one understands me or my grieve | 1 | 2 | 3 | 4 | 5 |
| 12. My emotional pain is difficult to endure | 1 | 2 | 3 | 4 | 5 |
| 13. I feel peaceful | 1 | 2 | 3 | 4 | 5 |
| 14. I am afraid to sleep | 1 | 2 | 3 | 4 | 5 |
| 15. I feel guilty | 1 | 2 | 3 | 4 | 5 |
| 16. I did not like it in the hospital | 1 | 2 | 3 | 4 | 5 |
| 17. I had no appetite | 1 | 2 | 3 | 4 | 5 |
| 18. We made the right decision when we chose hospice | 1 | 2 | 3 | 4 | 5 |
| 19. My room made me feel scared | 1 | 2 | 3 | 4 | 5 |
| 20. I was afraid of what was next | 1 | 2 | 3 | 4 | 5 |
| 21. I had special person(s) who made me feel cared for | 1 | 2 | 3 | 4 | 5 |

22. I have experienced changes which make me feel uneasy 1 2 3 4 5
23. I liked my room to be quiet and still 1 2 3 4 5
24. I would have like to have seen the doctor more often 1 2 3 4 5
25. The room temperature was fine 1 2 3 4 5
26. When the situation was over it has be difficult to resume my former
responsibilities 1 2 3 4 5
27. I can rise above this situation 1 2 3 4 5
28. The mood around me was depressing 1 2 3 4 5
29. I wanted my family to be more comfortable 1 2 3 4 5
30. The view around me inspired comfort 1 2 3 4 5
31. In retrospect, we 've had a good life 1 2 3 4 5
32. I felt out of place 1 2 3 4 5
33. I feel strong enough to do what need to be done
for my baby 1 2 3 4 5
34. I think about my baby having pain 1 2 3 4 5
35. I feel confident spiritually 1 2 3 4 5
36. I needed to be better informed about what was happing
with my baby 1 2 3 4 5
37. I feel helpless 1 2 3 4 5
38. As a couple we are okay with our personal relationship 1 2 3 4 5
39. The room smelled fresh 1 2 3 4 5
40. I feel lonely 1 2 3 4 5
41. I am now able to tell people what happened 1 2 3 4 5
42. I am depressed still 1 2 3 4 5
43. We have found meaning in this experience 1 2 3 4 5
44. My friends remember us with their cards and phone calls 1 2 3 4 5
45. My baby not being born alive made me feel sad 1 2 3 4 5
46. I think about the future a lot 1 2 3 4 5
47. My baby was clean and dry 1 2 3 4 5
48. I was concerned about finances 1 2 3 4 5

49. My God is helping me

1 2 3 4 5

Modify by: Sally Smith RN, BSN with written permission from Dr. Kathy Kolcaba: May 15, 2011. Associate Professor (Emeritus) The University of Akron Adjunct Faculty, Ursuline College. <http://www.TheComfortLine.com>

Appendix E
Demographic Information

APPENDIX E

Demographic Information:

1. Your gender; Male Female
2. Age:
3. Last grade completed
4. Circle the letters that best describe your ethnic group:

A. American Indian	E. Latino/Latina
B. Asian American	F. Mixed Ethnic Background
C. African-American/Black	G. Pacific Islander
D. Caucasian/White	H. Other _____

(Be Specify)
5. Circle the letter(s) that best describes your current employment status.

A. Full-Time	D. Unemployed
H.other_____	
B. Part-time	E. Disability
C. Self-employed	F. Student
6. Marital Status

A. Married/Partnered	D. Other_____
B. Single	
C. Divorced	
7. Explain At what gestation did you get your dagnosis_____
8. What options were your given?
 - a. Prenatal Hospice referral
 - b. Terminate
 - c. Other_____

Appendix F
Program Evaluation

APPENDIX F

Program Evaluation

Using a scale of 1 (not effective) through 5 (highly effective) please rate how effective prenatal hospice has been to enable you to meet the following objectives: (circle the number)

	Not Effective				Highly Effective
1. Define the importance of ongoing communication with the interdisciplinary team, patient, and your family throughout prenatal hospice process.	1	2	3	4	5
2. Identify factors that influence Communication in the hospice setting	1	2	3	4	5
3. Describe important factors in communicating bad news	1	2	3	4	5
4. Identify characteristics patient/family Expect of healthcare professional in caring For them in the hospital setting	1	2	3	4	5

Overall program Evaluation:

Using a scale of 1 (poor) through 5 (excellent), rate the following areas:

	Poor				Excellent
5. Usefulness of content to clinical practice	1	2	3	4	5
6. Timeframe of meeting with staff	1	2	3	4	5
7. Effectiveness as a learning event	1	2	3	4	5

Appendix G

Author's Permission

From: Kathy Kolcaba – kathykolcaba@yahoo.com

Date: 5/15/2011 @ 11:44 pm

Hello Sally,

You have my permission to use/adapt any existing comfort instrument for your research. I will be happy to help you do that if you think it would be helpful. I also like to have researchers collect data via a verbal rating scale to show concurrent validity. Good Luck with your research about this very important topic.

Dr. K.

Dr. Kathy Kolcaba
Associate Professor (Emeritus)
The University of Akron
Adjunct Faculty, Ursuline College
www.TheComfortLine.com

From: PaulBurnett <http://p.burnett@qut.edu.au>
Date: 5/22/2011 08:53 EDT

On Sun, May 22, 2011 at 7:47PM, Paul Burnett Wrote:

You have my permission to use CBI for your research with due acknowledgment,

Kind regards,
Paul

Professor Paul C. Burnett, Dean of Research and Research Training
Queensland University of Technology
Level 4, 88 Musk St. Kelvin Grove QLD 4059
Phone: (07) 31381303 Mob: 0418 248 134 Email: p.burnett@qut.edu.au
http://eprints.qut.edu.au/view/person/Burnett,_Paul.html.

Message View

Page 1 of 1

I would love any input you would like to offer. I am very new at this whole process.
Sally

On Sun, May 15, 2011 at 11:44 AM, Kathy Kolcaba wrote:

Hello Sally, You have my permission to use/adapt any existing comfort instrument for your research. I will be happy to help you do that if you think it would be helpful. I also like to have researchers collect data via a verbal rating scale to show concurrent validity. Good luck with your research about this very important topic.
Dr. K

Dr. Kathy Kolcaba
Associate Professor (Emeritus)
The University of Akron
Adjunct Faculty, Ursuline College
www.TheComfortLine.com

From: "sixsmiths6@charter.net" <sixsmiths6@charter.net>
To: Kathy Kolcaba <KathyKolcaba@yahoo.com>
Sent: Sat, May 14, 2011 11:04:39 AM
Subject: Research Tool

Dr. Kolcaba,

My name is Sally Smith, I have been a labor and delivery nurse for the past nine years. I am presently working on my thesis to complete my MSN in nursing education at Gardner-Webb University, in Boiling Springs North Carolina.

My request for you Dr. Kolcaba is that I wish to use your tool and theory in my research. I would like to have your permission to use and to modify your tool to fit the needs of my population.

The aim of my research is to examine how parents cope with the loss of an unborn child with lethal fetal anomalies, with the aid of prenatal hospice in the hospital setting. I would like to evaluate parents whom have used this type of program in order to see if their grief processes and coping mechanisms have had any improvement. Also to see if their experiences could have an impact on future advancements of this type of program being incorporated into a magnet hospitals.

You may reach me at sixsmiths6@charter.net or 171 Miles Dr. Spartanburg, SC 29306 or, my cell phone: 864-978-5781.

As part of my requirements I have to have a release from you allowing me to use your tool and to modify it, as needed.

Thank you in advance for your help in this matter. Please let me know as soon as you can. I must submit all information to GWU by May 23 - in order to proceed with my research.

Thank you
Sally Smith RN, BSN

<http://enhanced.charter.net/15583/messageview.html>

5/22/2011

RE: Message regarding "Core bereavement items"

Page 1 of 1

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From: sixsmiths6@charter.net
 To: "Paul Burnett" <p.burnett@qut.edu.au>
 Date: 05/22/2011 08:52:35 EDT
 Subject: **RE: Message regarding "Core bereavement items"**

Professor Burnett,
 Thank you very much. Is the below data how you would like to be acknowledge?
 Do I also have permission to modify if needed?
 Sally Smith

On Sun, May 22, 2011 at 7:47 PM, Paul Burnett wrote:

You have my permission to use the CBI for your research with due acknowledgment.

Kind regards,

Paul

Professor Paul C Burnett, Dean of Research and Research Training
Queensland University of Technology
Level 4, 88 Musk St KELVIN GROVE QLD 4059
Phone: (07) 3138 1303 Mob: 0418 248 134 Email: p.burnett@qut.edu.au
Publications:
http://eprints.qut.edu.au/view/person/Burnett,_Paul.html

From: sixsmiths6@charter.net [mailto:sixsmiths6@charter.net]
Sent: Friday, 20 May 2011 9:01 PM
To: Paul Burnett
Subject: Message regarding "Core bereavement items"

sixsmiths6@charter.net has sent you the following message via QUT ePrints:
 To Whom it May Concern: I am a graduate student at Gardner-Webb University in Boiling Springs NC. I am working on my master thesis this summer and would like to ask permission to use and or modify your core bereavement items tool in my study.PI ease let me know as soon as possible. Thank you Sally Smith

QUT ePrints
<http://eprints.qut.edu.au/>
epprints@qut.edu.au

<http://enhanced.charter.net/viewmessage?r=%3Crequest%3E%3Cmail%20action%3D%22...> 5/22/2011

