

Reducing Stress and Anxiety among Families by Introducing Prenatal Palliative Care

Kelly B. Abrams

Under Supervision of

Kimberly Callender

Second Reader

Kristin Seidl

Clinical Site Representative

Julianne Moss

A DNP Project Manuscript
Submitted in Partial Fulfillment of the Requirements for the
Doctor of Nursing Practice Degree

School of Nursing, University of Maryland at Baltimore
May 2023

Author Note

I have no conflicts of interest to disclose. Correspondence concerning this article should be addressed to Kelly B. Abrams, 655 W. Lombard St., Baltimore, MD 21201. Email: Kelly.brown@umaryland.edu

Abstract

Problem & Purpose: Critical congenital heart disease (CHD) is often diagnosed during the prenatal period. Families who receive this diagnosis are often not educated about what their lives will be like after the baby is born. Families of neonates with critical CHD at a large, academic medical center in Maryland report high levels of stress, anxiety, and difficulty coping with the CHD diagnosis and the postoperative process in the hospital. The purpose of this quality improvement initiative is to implement the practice change of a prenatal palliative care consult for families of patients with critical CHD. The main goal of the prenatal palliative care consult is to decrease the levels of stress and anxiety and improve coping in families of patients with critical CHD.

Methods: Families met with the cardiac surgeons and then the clinical coordinator to discuss the predicted postoperative course. Prior to this meeting, a survey was sent to families via REDCap which included the following instruments: Brief COPE Inventory and Depression, Anxiety and Stress Scale (DASS-21). The meeting with the clinical coordinator included the prenatal palliative care consult. Families were provided with resources, psychosocial support, and care coordination. The same survey was sent to families after the consult.

Results: Six referrals to palliative care were made and four consults were completed which means that 66.7% of eligible participants received a prenatal palliative care consult. Pre and post consult surveys were sent to all families that received a consult and two families completed the surveys which is a 50% response rate. The average anxiety, stress, and depression scores decreased on the DASS-21 survey from 7 ± 1.41 to 3 ± 1.41 , 11 ± 1.41 to 7 ± 1.41 , and 18 ± 5.66 to 14 ± 0 , respectively. The Brief COPE survey results showed improvement in some coping mechanisms scores including instrumental support, acceptance, and positive reframing.

Conclusions: Due to the limited number of eligible participants in this project, it is difficult to make any sweeping conclusions. There is potential that a prenatal palliative care consult can decrease stress and anxiety and improve coping in families of patients with critical CHD based on the findings.

Keywords: palliative care, congenital heart disease, coping, stress, anxiety

Reducing Stress and Anxiety among Families by Introducing Prenatal Palliative Care

Congenital heart disease (CHD) is the most common congenital abnormality in infants and many of these infants require surgical intervention in the neonatal period (McMahon & Chang, 2019). Critical congenital heart disease (CHD) is a congenital abnormality that is often diagnosed during the prenatal period. Critical CHD is a term which encompasses those patients who require a surgical or trans-catheter intervention prior to hospital discharge after birth (Mazwi et al., 2017). During the prenatal period, families meet with cardiologists and cardiothoracic surgeons to discuss the diagnosis and next steps. The focus of prenatal cardiac care is the immediate surgical interventions necessary for survival. The families are often not educated about what their lives will be like after the baby is born and the resources available to them. Introducing palliative care during the prenatal period is essential to providing families with resources, support, and access to all of their options during this lifechanging time. The impact of a complex cardiac diagnosis upon a family along with frequent morbidities that result in prolonged hospital stays is significant and needs to be portrayed as early as possible to families (Davis et al., 2019). The early introduction of pediatric palliative care can improve quality of life for families, communication among caregivers, and symptom management for pediatric patients (Hancock et al., 2018). Hancock et al. found that maternal anxiety was significantly reduced, and adaptive coping mechanisms improved significantly in patients who received early palliative care versus those who received the standard care (2018).

This quality improvement project took place in a congenital heart program at a large, urban academic medical center in Maryland. The population was expectant parents of neonates with CHD. Palliative care is currently not integrated into the prenatal cardiac care program. Families report stress, anxiety, and difficulty coping with the CHD diagnosis and the pre and

postoperative process in the hospital. The root causes of this problem are a lack of early introduction to palliative care and a lack of continuity of care leading to stress, anxiety, and poor coping mechanisms for families of patients with critical congenital heart disease.

The purpose of this quality improvement project was to implement the practice change of a prenatal palliative care consult for families of patients with congenital heart disease. The main process goals were that 100% of expectant parents of neonates with critical CHD will receive a palliative care consult prenatally and that a palliative care consult will be offered to 100% of patients with critical CHD diagnosed prenatally. The first outcome goal was that 100% of families of neonates with critical CHD will report decreased stress and anxiety on the DASS-21 survey after integration of palliative care prenatally. The second outcome goal was that 100% of families of neonates with critical CHD will report improved coping on the Brief COPE inventory after integration of palliative care prenatally.

Available Knowledge

Pediatric palliative care introduced during the prenatal period was effective in decreasing stress and anxiety for the families of neonates with CHD. Palliative care was introduced after the prenatal visits with the pediatric cardiologist and cardiothoracic surgeons. Introducing palliative care during this time provided families with information they could use to prepare for the birth and surgery of their neonate with CHD and the resources to cope during this stressful time. The current evidence supports this practice change by showing that early palliative care consultation decreases parental anxiety and stress. One randomized controlled trial (Hancock et al., 2018), one quasi-experimental study (Callahan et al., 2019), one systematic review (Kasparian et al., 2019), and two non-experimental studies (Fonseca et al., 2012 & Rychik et al., 2013) were reviewed and synthesized supporting this practice change (Appendix A).

Hancock et al. (2018) found that early palliative care consultation decreased maternal anxiety significantly ($p=0.02$), improved maternal positive reframing ($p=0.03$), and showed a positive change in perceived communication and family relationships. Callahan et al. (2019) found that parents of infants with congenital heart disease experienced decreased stress ($p=0.01$) when provided with early palliative care. Kasparian et al. (2019) found that psychological interventions reduce anxiety in parents of neonates with congenital heart disease. Fonseca et al. (2012) found that parents of infants with congenital anomalies experience a significant amount of psychological distress ($p=0.003$) and a prenatal diagnosis versus postnatal is associated with a higher psychological quality of life ($p=0.045$). Rychik et al. (2013) found that pregnant mothers of fetuses with congenital heart disease experience significant post-traumatic stress, depression, and anxiety. Davis et al. (2019) conducted a quality improvement project over a 40-month period in a tertiary pediatric medical center. Patients with single ventricle physiology were provided with a palliative care consult. Early palliative care consults allowed for more family and patient support starting at an earlier stage in life. There is good and consistent evidence to support the practice change of early palliative care and family support for families of neonates with congenital heart disease to alleviate stress and anxiety (Appendix B).

Rationale

The Knowledge to Action (KTA) framework was chosen to guide the implementation of this pediatric palliative care intervention. The KTA framework was developed by Graham et al. in 2006. The framework includes two major components, knowledge creation and the action cycle, which are synergistic. Knowledge creation is represented as a funnel and the application of knowledge (action) surrounds the funnel. Knowledge creation involves tailoring knowledge through the concepts of knowledge inquiry, synthesis, and tools/products. The action cycle

surrounds the knowledge creation funnel and includes the steps necessary leading to implementation or application of knowledge (Graham et al., 2006). This theory helps to explain the intervention because it follows the action cycle accordingly. A problem was identified, knowledge inquiry and synthesis occurred through integrative evidence review and critical appraisal, knowledge was adapted to the local context, and barriers have been assessed. The identified problem was expectant families of neonates with CHD lack support and guidance during the prenatal period. Evidence was reviewed and synthesized to determine how to alleviate this problem. Prenatal palliative care has been found to decrease the stress and anxiety of families therefore this was shared with site stakeholders. In addition, barriers to the proposed intervention were assessed. The intervention was then implemented, knowledge use was monitored by tracking process measures, and outcomes have been evaluated.

Methods

Context

This quality improvement project took place in the congenital heart program at a large, urban academic medical center. The current site processes and structures involves the fetal heart center at the same medical center referring patients to the cardiothoracic surgeons when they are identified as having a neonate with a congenital heart defect requiring surgical intervention soon after birth. The cardiothoracic surgery clinical coordinator receives the referrals from the director of the fetal heart program and reaches out to the families and the cardiothoracic surgeons to coordinate meetings. The expectant parents then meet with the cardiothoracic surgeons to discuss the congenital heart defect in detail and the surgical plans. All eligible participants were included in this project because the clinical coordinator received the neonatal cardiac surgery referrals and communicated this with the project lead.

Intervention

This project was implemented over a 15-week period. Members of the team included a Doctor of Nursing Practice student (project lead), the clinical site representative (pediatric cardiac surgery nurse practitioner), the cardiothoracic surgery clinical coordinator, and sponsor (director of patient care services). Prior to the implementation process, the project lead and the clinical coordinator met with the fetal cardiologist and cardiothoracic surgeons to educate about prenatal palliative care and discuss the goals of this quality improvement project. This action helped to achieve buy-in from key stakeholders and helped with collaboration and communication during the implementation process.

After patients were referred for cardiac surgery and a cardiac surgery consult was completed, the clinical coordinator referred eligible patients to the project lead. An email was sent to families with introductory information about palliative care and it also contained the pre-implementation survey. The survey included the following instruments: Depression, Anxiety and Stress Scale (DASS-21) and the Brief COPE Inventory (Appendices C & D). Collaboration and open communication with the clinical coordinator to ensure the surveys are sent to all eligible families was an important implementation strategy that was used. Families met with the clinical coordinator during their third trimester to provide updated information about plan of care and for a tour of the pediatric cardiac intensive care unit (PCICU). After completion of the tour, families were introduced to palliative care through a palliative care consult. The palliative care consult included discussions about goals of care, details about the hospitalization and what to expect, psychosocial support, and coordination of care. The same post-implementation survey was sent to patients after the palliative care consult to evaluate if the introduction to palliative care decreased stress and anxiety, and improved coping. The feedback and opinions of the

families was very important during the implementation process. Families were encouraged to be active participants in the care of their neonates and provide feedback on the implementation effort. The buy-in and engagement from the clinical coordinator and cardiothoracic surgeons early in the implementation process was important to the sustainability of this practice change.

Measures

The structure measures during implementation included the creation and distribution of palliative care educational material and the creation and implementation of parental surveys. There were no costs associated with this intervention which contributed to the engagement and buy-in from stakeholders. The process measures included adherence to palliative care consult initiation (the number of expectant parents of neonates with critical CHD that had a palliative care consult prenatally / the number of expectant parents of neonates with critical CHD total) pre-implementation and during implementation. This measure resulted in a ratio that was used to calculate a percentage.

The outcome measures included decreased reported levels of stress and anxiety as well as improved coping after integration of palliative care. The DASS-21 and Brief COPE are validated tools to measure stress, anxiety, and coping in individuals. These tools were used in the studies described previously and have shown validity and reliability. The outcome measures resulted in a ratio that was used to calculate a percentage for each measure. Completion of surveys was measured by looking at the response rate (number of completed surveys / the total number of surveys sent to families).

Study of the Intervention

Eligible participants were sent an email by the cardiothoracic surgery clinical coordinator with details about palliative care. The email contained a unique link to the coping and anxiety surveys which were administered through REDCap. The email asked participants to complete the survey prior to the palliative care consult. Survey data was collected through REDCap, a HIPAA compliant and password-protected database, and was measured and analyzed by the project lead. Privacy of eligible participants was protected by allowing participants to complete the surveys at home or in a private conference room on site. Facilitators to data collection included the easy accessibility of the electronic coping and anxiety surveys. The main barrier to data collection was the small sample size available. It was determined that the observed outcomes were due to the intervention because it was the only variable that was changed in the prenatal cardiac surgery workflow.

Analytics

Qualitative and quantitative methods were used to draw inferences from the project data. Qualitative data in the form of informally collected anecdotal data from parents. The adherence to initiating prenatal palliative care consults was demonstrated through a run chart showing the frequency of palliative care consults and the percentage of patients that had a palliative care consult initiated versus the total number of eligible patients. The run chart displays the data on a weekly basis and illustrates the change over time during the 15-week project period. In addition, the response rate on the pre and post implementation surveys was compared to the total number of families who received implementation surveys. The response rate was collected and analyzed over the 15-week project timeline. Pre-implementation and post-implementation survey scores were compared to look for a change in survey score results over time.

Ethical Considerations

This quality improvement project was conducted in accordance with the required ethical standards. Data privacy/confidentiality was maintained following the Health Insurance Portability and Accountability Act (HIPAA). Surveys were completed through REDCap, a HIPAA compliant password-protected database to protect confidentiality. Potentially identifiable data (date of birth) collected through the online survey is coded in REDCap to protect confidentiality. This project was conducted under a Non-human Subject's Research determination from the Human Research Protections Office (HRPO) of the UMSOM Institutional Review Board (IRB).

Results

Six families were eligible for a prenatal palliative care consult during the 15-week project period. Four of the six eligible families received a palliative care consult which is 66.7% (Figure 4). The process goal of 100% of expectant parents of neonates with critical CHD will be referred for a palliative care consult was met. 100% of eligible families were referred for palliative care but only 66.7% of eligible families had a consult completed. The percentage of families who received a prenatal palliative care consult on a weekly basis is illustrated in the run chart in Figure 1. No trends or shifts can be identified on the run chart.

Baseline data was collected from two eligible families whose neonates had cardiac surgery within the first 3-week period of the implementation process. These families had already completed the appointment with the clinical coordinator prior to the project implementation start date therefore a palliative care consult could not be offered. One of the main outcome goals was that by December 2022, 100% of families would complete the pre and

post consult surveys. Six families were eligible for participation in this project and four families had palliative care consults completed. Pre and post consult surveys were sent to the four families, and two pre consult surveys and two post-consult surveys were completed which is a response rate of 50%. Data showing the number of surveys sent to eligible participants versus the number of surveys completed can be found in Figure 2.

The outcome goals of 100% of families of neonates with critical CHD will report decreased stress and anxiety on the DASS-21 and improved coping on the Brief COPE after integration of palliative care were assessed and analyzed. There was an improvement in the depression, anxiety, and stress scores on the DASS-21 survey for the two families that completed the pre and post consult surveys (Figure 3). The Brief COPE survey results show improvement in some coping mechanisms scores including instrumental support, acceptance, positive reframing, and planning. Scores from the Brief COPE pre and post consult can be found in Table 1.

Discussion

Prenatal palliative care consults were implemented successfully to families of neonates with critical CHD. 100% of eligible patients were referred for a prenatal palliative care consult which shows that it can be easily added to the congenital heart program workflow. After completing a prenatal palliative care consult, the anxiety, stress, and depression scores on the DASS-21 survey improved for the two families who completed surveys. The average anxiety, stress, and depression scores decreased from 7 ± 1.41 to 3 ± 1.41 , 11 ± 1.41 to 7 ± 1.41 , and 18 ± 5.66 to 14 ± 0 , respectively. Some coping mechanisms were also improved on the Brief COPE survey. These results are similar to results achieved by Callahan et al (2019) and Hancock et al (2018). During the implementation, the eligible number of participants decreased substantially compared with the 12 months prior to implementation leading to a smaller than expected sample

size. Small sample size is a limitation of this project. There were no costs associated with this quality improvement project which is beneficial to the sustainability of this project.

Conclusions

Due to the limited number of eligible participants in this project, it is difficult to make any sweeping conclusions. Nonetheless, there is potential that a prenatal palliative care consult can decrease stress and anxiety and improve coping in families of patients with critical CHD based on the findings.

A prenatal palliative care consult is a welcome addition to the prenatal care provided to families with neonates with congenital heart defects. This quality improvement project has added to the growing knowledge and research that supports palliative care in the pediatric population. There is so much more work that is needed to show the positive effects that palliative care has on patients and their families.

The strengths of this project include that a prenatal consult can be added without significant cost to the medical institution, and it does not have a negative impact on workflow. A palliative care consult can be easily added into an existing prenatal cardiac surgery program and provides significant assistance and stress relief to families. This project can be sustained through the dedication of the clinical coordinator who will continue to include palliative care during the prenatal tour. There is limited work that has been done in this field therefore more work needs to be done to illustrate the effectiveness of palliative care prenatally.

References

- Callahan, K., Steinwurtzel, R., Brumarie, L., Schechter, S., & Parravicini, E. (2019). Early palliative care reduces stress in parents of neonates with congenital heart disease: Validation of the “Baby, Attachment, Comfort Interventions.” *Journal of Perinatology*, 39, 1640-1647. <https://doi.org/10.1038/s41372-019-0490-y>
- Davis, J. M., Bass, A., Humphrey, L., Texter, K., & Garee, A. (2019). Early integration of palliative care in families of children with single ventricle congenital heart defects: A quality improvement project to enhance family support. *Pediatric Cardiology*, 41, 114-122. <https://doi.org/10.1007/s00246-019-02231-y>
- Fonseca, A., Nazare, B., & Canavarro, M. C. (2012). Parental psychological distress and quality of life after a prenatal or postnatal diagnosis of congenital anomaly: A controlled comparison study with parents of healthy infants. *Disability and Health Journal*, 5, 67-74. <https://doi.org/10.1016/j.dhjo.2011.11.001>
- Graham, I. D., Logan, J., Harrison, M. B., Straus, S. E., Tetroe, J., Caswell, W., & Robinson, N. (2006). Lost in knowledge translation: Time for a map? *The Journal of Continuing Education in the Health Professions*, 26(1), 13-24. DOI: 10.1002/chp.47
- Hancock, H. S., Pituch, K., Uzark, K., Bhat, P., Fifer, C., Silveira, M., Yu, S., Wlech, S., Donohue, J., Lowery, R., & Aiyagari, R. (2018). A randomized trial of early palliative care for maternal stress in infants prenatally diagnosed with single-ventricle heart disease. *Cardiology in the Young*, 28, 561-570. <https://doi.org/10.1017/S1047951117002761>

Kasparian, N. A., Kan, J. M., Sood, E., Wray, J., Pincus, H. A., & Newburger, J. W. (2019).

Mental health care for parents of babies with congenital heart disease during intensive care unit admission: Systematic review and statement of best practice. *Early Human Development*, 139, 1-20. <https://doi-org.proxy-hs.researchport.umd.edu/10.1016/j.earlhumdev.2019.104837>

Mazwi, M. L., Henner, N., & Kirsch, R. (2017). The role of palliative care in critical congenital heart disease. *Seminars in Perinatology*, 41, 128-132.

<http://dx.doi.org/10.1053/j.semperi.2016.11.006>

McMahon, E. & Chang, Y-S. (2020). From surviving to thriving – Parental experiences of hospitalized infants with congenital heart disease undergoing cardiac surgery: A qualitative synthesis. *Journal of Pediatric Nursing*, 51, 32-41.

<https://doi.org/10.1016/j.pedn.2019.12.010>

Rychik, J., Donaghue, D. D., Levy, S., Fajardo, C., Combs, J., Zhang, X., Szwasz, A., & Diamond, G. S. (2013). Maternal psychological stress after prenatal diagnosis of congenital heart disease. *The Journal of Pediatrics*, 162(2), 302-307.

<http://dx.doi.org/10.1016/j.jpeds.2012.07.023>

Table 1

Brief Cope Inventory scores before and after palliative care consult

Brief Cope Inventory		
	Pre-Consult	Post-Consult
Adaptive		
Active coping	3	2.5
Emotional support	2.5	2
Instrumental support	2	2.5
Positive reframing	2.5	3.5
Planning	4	2.5
Humor	1	1
Acceptance	2.5	3
Religion	3.5	1.5
Problematic		
Self-distraction	2.5	3.5
Denial	1	1
Substance use	1	1
Behavior disengagement	1	1
Venting	3	1
Self-blame	3	1

Figure 1

Run chart monitoring the percent of families who received a palliative care consult

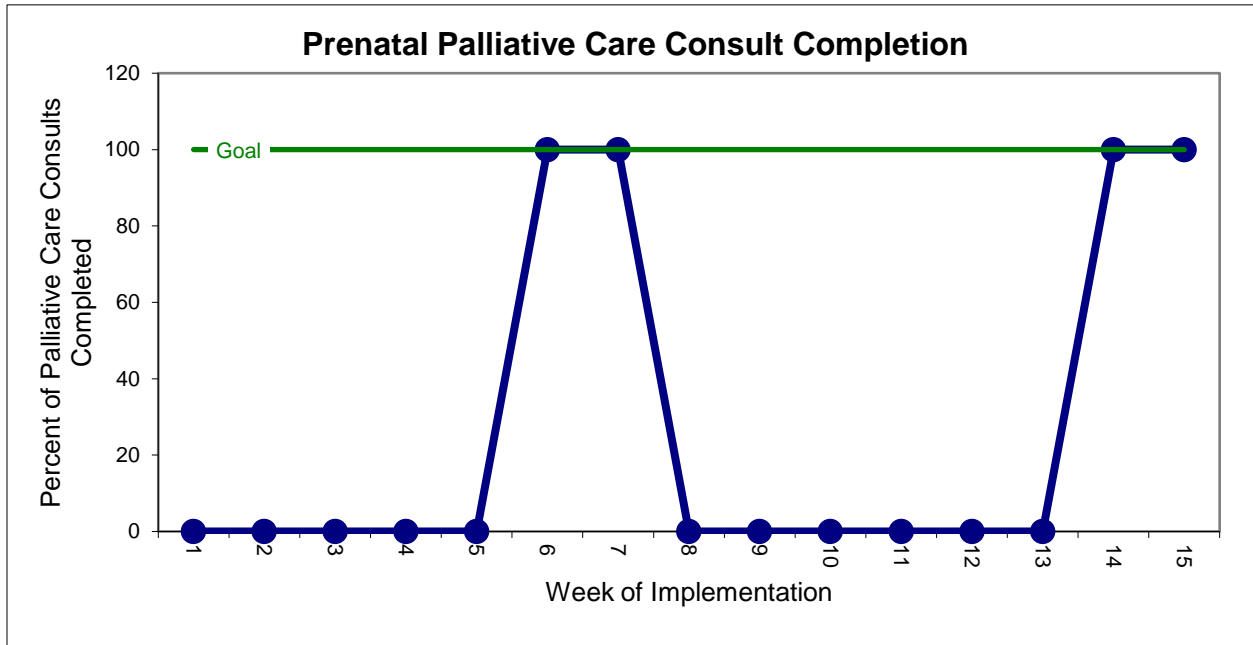


Figure 2

Monitoring the outcome goal of surveys sent versus surveys completed

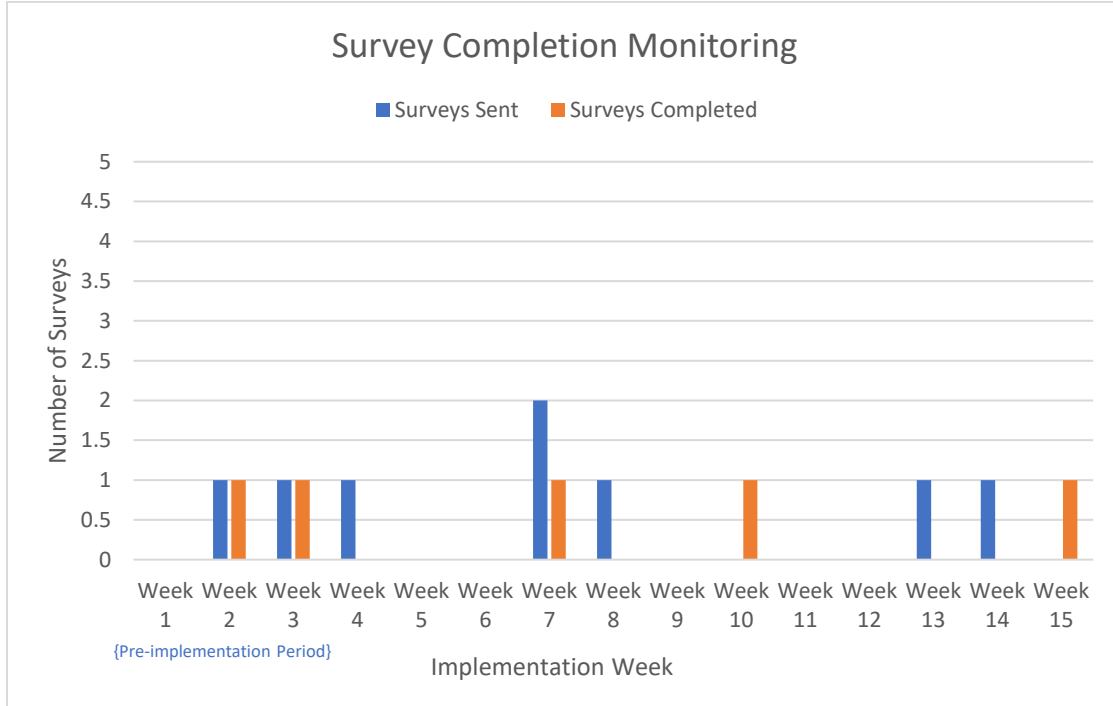


Figure 3

DASS-21 survey results before and after palliative care consult

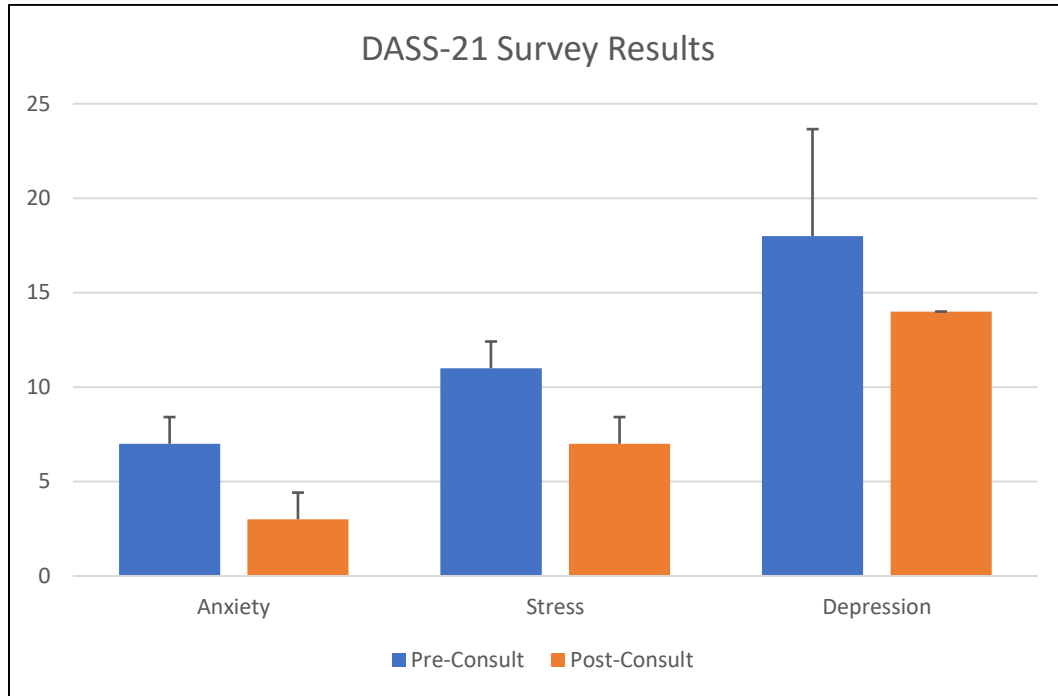
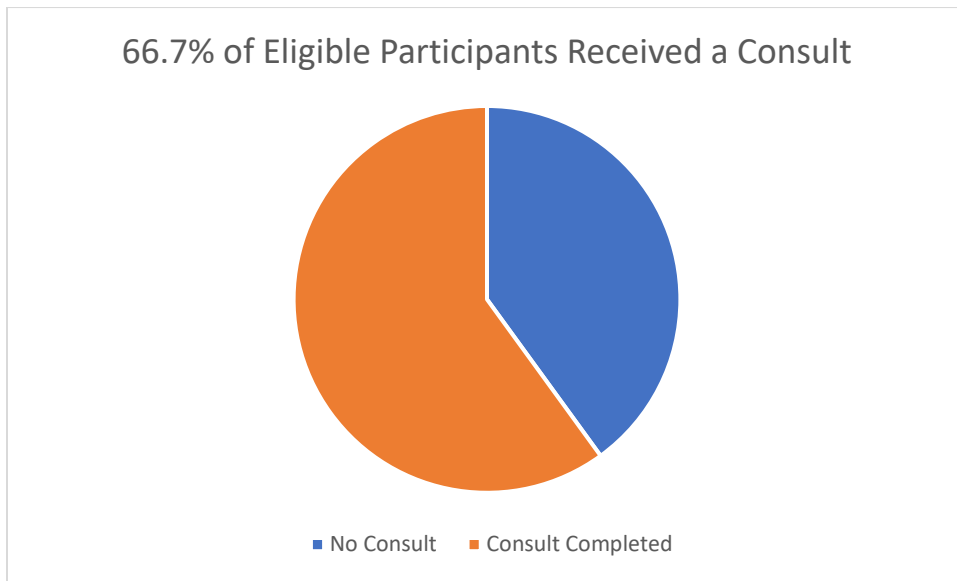


Figure 4

Pie chart illustrating eligible participants who received a consult



Appendix A

Evidence Review Table

<p>Citation: Callahan, K., Steinwurtzel, R., Brumarie, L., Schechter, S., & Parravicini, E. (2019). Early palliative care reduces stress in parents of neonates with congenital heart disease: Validation of the “Baby, Attachment, Comfort Interventions.” <i>Journal of Perinatology</i>, 39, 1640-1647. https://doi.org/10.1038/s41372-019-0490-y</p>					<p>Level and Quality II-B</p>
Purpose/ Hypothesis	Type of Evidence Research Design	Sample – Population, Size, Setting	Intervention/Procedures	Primary Outcome/Measures	Results/Conclusions
<p>To test an innovative method of early palliative care in reducing psychological distress in parents of neonates with congenital heart disease</p>	<p>Research: Quasi-experimental Prospective cohort study</p>	<p>Sampling Technique: convenience</p> <p>Participants: # eligible: 91 # accepted: 77 # in control: 51 # in intervention: 26</p> <p>It does not appear that participants were randomly assigned to intervention and control groups</p> <p>Power analysis: To achieve 80% power, required sample size of 70 subjects needed for two-sided significance level of 0.05</p> <p>Group Homogeneity: No significant difference in demographic data or neonates’ clinical severity between study groups</p> <p>Setting: recruitment occurred over a 1-year period starting</p>	<p>Control: parents received standard of care</p> <p>Intervention: interdisciplinary interventions aimed at improving neonatal comfort and parenting experience; interventions occurred at least twice per week</p> <p>Intervention fidelity: Goals of care and family concerns were discussed at the beginning of the intervention. BACI (baby, attachment, comfort interventions) method was used which includes promotion of bonding (skin-to-skin, changing diapers, bathing), feeding (nonnutritive suck, colostrum care), and psychological support by social work, psychologist, and chaplain</p>	<p>DV: parental stress reflected on the NUPS questionnaire DV Measure: Psychological distress was evaluated at admission and discharge using the Neonatal Unit Parental Stressor Scale (NUPS) and Depression Anxiety Stress Index-21 (DASS-21)</p> <p>NUPS and DASS-21 have established reliability and validity</p>	<p>Statistical Results: Stress decreased in the intervention group according to the NUPS questionnaire (p=0.01) but not in the control group</p> <p>Stress also decreased on the DASS-21 in the intervention group (p<0.01) but there was not a significant decrease in anxiety or depression in either group</p> <p>Effect size was 0.53 for NUPS overall stress and 0.30 for DASS-Stress</p> <p>Conclusions: Early palliative care reduces stress in parents of neonates with congenital heart disease. More work is needed to assess anxiety and depression in this population.</p>

		in June 2017 at a tertiary medical center			
--	--	---	--	--	--

<p>Citation: Davis, J. M., Bass, A., Humphrey, L., Texter, K., & Garee, A. (2019). Early integration of palliative care in families of children with single ventricle congenital heart defects: A quality improvement project to enhance family support. <i>Pediatric Cardiology</i>, 41, 114-122 https://doi.org/10.1007/s00246-019-02231-y</p>					<p>Level and Quality V-B</p>
Purpose/ Hypothesis	Type of Evidence Research Design	Sample – Population, Size, Setting	Intervention/Procedures	Primary Outcome/Measures	Results/Conclusions
<p>To describe a quality improvement project of early integration of pediatric palliative care (PPC) with families of children with single ventricle congenital heart defects (SVCHD)</p>	<p>Practice evidence</p>	<p>Sampling Technique: convenience</p> <p>Sample: 103 patients with SVCHD</p> <p>Setting: data collected over 40-month period at one tertiary pediatric medical center</p>	<p>Control: N/A</p> <p>Interventions: -Palliative care program expansion through an additional staff member added to the PPC team -PPC team was educated about single ventricle physiology -Established a standard workflow for PPC team to be connected to patients with SVCHD -Education about PPC principles given to cardiology providers and other bedside caregivers</p>	<p>Primary outcome measure: percentage of hospitalized patients with SV physiology who received a PPC consultation Process measure: number of days between admission to the CTICU after birth and PPC consultation</p>	<p>Statistical Results: PPC consultation increased significantly over the study period to nearly 100% compliance (from 25%)</p> <p>Median and mean days to consult decreased dramatically from median of 54 days and mean of 85 days prior to intervention to a median of 2 days and mean of 12 days following intervention.</p> <p>Conclusions: Patients are being followed by the PPC team at an earlier age and stage in their medical journey which allows more time for family and patient support.</p>

<p>Citation: Fonseca, A., Nazare, B., & Canavarro, M. C. (2012). Parental psychological distress and quality of life after a prenatal or postnatal diagnosis of congenital anomaly: A controlled comparison study with parents of healthy infants. <i>Disability and Health Journal</i>, 5, 67-74. https://doi.org/10.1016/j.dhjo.2011.11.001</p>					<p>Level and Quality III-B</p>
Purpose/ Hypothesis	Type of Evidence Research Design	Sample – Population, Size, Setting	Intervention/Procedures	Primary Outcome/Measures	Results/Conclusions
<p>To characterize the maternal and paternal psychological distress and quality of life in the early postdiagnosis stage after a prenatal or postnatal diagnosis of a congenital anomaly in comparison with a group of parents of healthy infants in the same developmental period.</p>	<p>Research: nonexperimental study</p> <p>Design: Cross-sectional controlled comparison</p>	<p>Sampling Technique: convenience</p> <p>Participants: # eligible: 169 couples # accepted: 84 couples # in control: 42 # in intervention: 42 (inclusion criteria was having an infant with a prenatal or postnatally identified congenital anomaly)</p> <p>Power analysis: post hoc power calculations made with a power of .80 or greater indicated medium to large effects could be detected</p> <p>Group Homogeneity: no significant differences between groups in regard to sociodemographic and clinical characteristics</p> <p>Setting: data collection occurred between September 2009 and April 2011 at two medical centers in Portugal</p>	<p>Control: parents of healthy infants completed the Brief Symptom Inventory-18 and the World Health Organization Quality of Life-Brief instrument</p> <p>Intervention: 42 couples whose infants were prenatal or postnatally diagnosed with a congenital anomaly responded to the Brief Symptom Inventory-18 and to the World Health Organization Quality of Life-Brief instrument</p> <p>Analysis conducted using IBM SPSS</p>	<p>Primary outcome measure: Psychological distress measured using the Brief Symptom Inventory (BSI-18)</p> <p>Secondary outcome measure: Quality of life was assessed using the World Health Organization Quality of Life brief instrument (WHOQOL-BREF)</p>	<p>Statistical Results: Parents whose infants were diagnosed with a congenital anomaly presented higher levels of distress than the parents with healthy infants (p=0.003)</p> <p>Receiving the diagnosis in the prenatal period was associated with higher maternal psychological quality of life (p=0.045).</p> <p>The study did not have enough power given the sample size</p> <p>Conclusions: Parents with infants diagnosed with a congenital anomaly experience significant psychological distress compared with parents with healthy infants. Health professionals must recognize that parents are at increased risk of developing psychopathological symptoms and counseling may be beneficial.</p>

<p>Citation: Hancock, H. S., Pituch, K., Uzark, K., Bhat, P., Fifer, C., Silveira, M., Yu, S., Welch, S., Donohue, J., Lowery, R., & Aiyagari, R. (2018). A randomized trial of early palliative care for maternal stress in infants prenatally diagnosed with single-ventricle heart disease. <i>Cardiology in the Young</i>, 28, 561-570. https://doi.org/10.1017/S1047951117002761</p>					<p>Level and Quality I-B</p>
<p>Purpose/Hypothesis</p>	<p>Type of Evidence Research Design</p>	<p>Sample – Population, Size, Setting</p>	<p>Intervention/Procedures</p>	<p>Primary Outcome/Measures</p>	<p>Results/Conclusions</p>
<p>To assess the benefit of early pediatric palliative care consultation on stress in mothers of neonates with single ventricle congenital heart disease (CHD)</p>	<p>Research: Pilot randomized controlled trial</p>	<p>Sampling Technique: convenience</p> <p>Participants: mothers referred to congenital heart center between April 2013 and August 2015</p> <p># eligible: 56 # accepted: 38 # in control: 20 # in intervention: 18</p> <p>Power analysis: a sample size of 38 can achieve 77% power to detect a 25% mean difference in total score between study groups</p> <p>Group Homogeneity: No significant differences between maternal demographic data and the infants' clinical characteristics between groups</p> <p>Setting: congenital heart center at a large, pediatric medical center</p>	<p>Control: usual care (no or late pediatric palliative care consultation)</p> <p>Intervention: early pediatric palliative care consultation before first surgery</p> <p>Intervention Details: Eligible mothers approached at follow-up fetal cardiac visit and invited to complete survey.</p> <p>Intervention group participants received an initial palliative care consultation when the neonate was admitted for planned surgery</p> <p>The second survey was completed on neonatal discharge (or 30 days after first surgery)</p>	<p>DV: overall maternal stress defined as combined anxiety, depression, coping, quality of life and family functioning scores</p> <p>Instruments used: Anxiety: State-Trait Anxiety Inventory (STAI) Depression: Beck Depression Inventory-II (BDI) Coping: Brief COPE Maternal health-related quality of life: PedsQL Family Impact Module (maternal functioning subscales) Perceived family functioning: PedsQL Family Impact Module (family functioning subscales) All outcomes assessed during pregnancy and 30 days postpartum.</p>	<p>Statistical Results: Significant reduction in maternal anxiety scores (from antenatal to postnatal assessment) for intervention compared with control group (7.6 reduction for intervention group vs 0.3-point reduction for control group, p=0.02)</p> <p>Intervention group reported greater positive reframing compared with control group (p=0.03)</p> <p>No significant difference in change in overall 'maternal stress' (primary outcome), depression or HRQOL scores between groups reported</p> <p>Power is not sufficient if based on conventional 80% power</p> <p>Conclusions Mothers of infants with single-ventricle disease experience significant depression and anxiety prenatally. Early palliative care decreased maternal anxiety, improved maternal positive reframing, and improved communication and family relationships.</p>

<p>Citation: Kasparian, N. A., Kan, J. M., Sood, E., Wray, J., Pincus, H. A., & Newburger, J. W. (2019). Mental health care for parents of babies with congenital heart disease during intensive care unit admission: Systematic review and statement of best practice. <i>Early Human Development, 139</i>, 1-20. https://doi-org.proxy-hs.researchport.umd.edu/10.1016/j.earlhumdev.2019.104837</p>					<p>Level and Quality II-B</p>
<p>Purpose/ Hypothesis</p>	<p>Type of Evidence Research Design</p>	<p>Sample – Population, Size, Setting</p>	<p>Intervention/Procedures</p>	<p>Primary Outcome/Measures</p>	<p>Results/Conclusions</p>
<p>To inform best practice principles for the mental health care of parents and their infants with congenital heart disease through a systematic review of all relevant evidence.</p>	<p>Systematic review of a combination of RCTs and quasi-experimental studies</p>	<p>Systematic search completed in October 2018 of 6 electronic databases</p> <p>Study eligibility: controlled trials delivering a psychological intervention for parents of infants (aged 0-12 months) with a congenital anomaly</p> <p>5 articles met inclusion criteria (2 randomized and 3 non-randomized)</p>	<p>Intervention: early palliative care consultation involving the teaching of coping strategies, promoting effective mother-infant interactions, and promoting self-efficacy of parents</p>	<p>Primary outcome of studies: anxiety defined by scores on the validated State-Trait Anxiety Inventory (4) or structured clinical interviews (1)</p> <p>Secondary outcomes: depressive symptoms, psychological stress or distress, health-related quality of life, coping responses, and parent satisfaction</p>	<p>Conclusions Data supports the efficacy of psychological interventions in reducing parental anxiety and improving coping, parenting confidence, and satisfaction with clinical care.</p>

<p>Citation: Rychik, J., Donaghue, D. D., Levy, S., Fajardo, C., Combs, J., Zhang, X., Szwest, A., & Diamond, G. S. (2013). Maternal psychological stress after prenatal diagnosis of congenital heart disease. <i>The Journal of Pediatrics</i>, 162(2), 302-307. http://dx.doi.org/10.1016/j.jpeds.2012.07.023</p>					<p>Level and Quality III-B</p>
Purpose/ Hypothesis	Type of Evidence Research Design	Sample – Population, Size, Setting	Intervention/Procedures	Primary Outcome/Measures	Results/Conclusions
<p>To characterize the psychological stress on the mother of a fetus with a prenatal diagnosis of congenital heart disease (CHD) and to explore how partner satisfaction and coping styles potentially moderate this stress.</p>	<p>Research: nonexperimental study</p> <p>Cross-sectional survey</p>	<p>Sampling Technique: convenience</p> <p>Participants: pregnant mothers receiving prenatal diagnosis and management of CHD</p> <p># eligible: 88 # accepted: 61 # in intervention: 59</p> <p>Setting: Fetal Heart Program at a large, urban pediatric medical center</p>	<p>Intervention: surveys administered in person by a research assistant between January 2009 and June 2010</p> <p>Control: normal control data was obtained from prior research</p>	<p>DV: psychological stress measured using instruments presented in a survey</p> <p>Surveys included the following instruments:</p> <p>Impact of Events Scale-Revised which assesses perceived post-traumatic stress</p> <p>State-Trait Anxiety Index to assess current anxiety symptoms</p> <p>Beck Depression Index II to assess the severity of depressive symptoms</p> <p>COPE Inventory to assess coping responses</p> <p>Dyadic Adjustment Scale to measure partner adjustment</p>	<p>Statistical Results: Clinically important traumatic distress was seen in 39%, depression in 22%, and state anxiety in 31%</p> <p>Feelings of denial were most associated with increased traumatic stress, anxiety, and depression (p<.01)</p> <p>*Results were compared with a current study sample of women of similar age who were pregnant with a healthy fetus showing significantly higher anxiety (p<.001) and significantly higher depressive symptoms (p<.003)</p> <p>Conclusions: post-traumatic stress, depression, and anxiety are common after prenatal diagnosis of CHD. Healthy partner relationships and positive coping mechanisms can act as buffers.</p>

Appendix B

Evidence Synthesis Table

Category (Level Type)	Total Number of Sources/Level	Overall Quality Rating	Synthesis of Findings
Level I - Experimental study · Randomized Controlled Trial (RCT) · Systematic review of RCTs with or without meta-analysis	1 RCT	B	Hancock et al. (2018) found that early palliative care consultation decreased maternal anxiety significantly (p=0.02), improved maternal positive reframing (p=0.03), and showed a positive change in perceived communication and family relationships.
Level II · Quasi-experimental studies · Systematic review of a combination of RCTs and quasi-experimental studies, or quasi-experimental studies only, with or without meta-analysis	1 Quasi-experimental and 1 systematic review	B	Callahan et al. (2019) found that parents of infants with congenital heart disease experienced decreased stress (p=0.01) when provided with early palliative care. Kasparian et al. (2019) found that psychological interventions reduce anxiety in parents of neonates with congenital heart disease.
Level III · Non-experimental study · Systematic review of a combination of RCTs, quasi-experimental, and non-experimental studies, or non-experimental studies only, with or without meta-analysis · Qualitative study or systematic review of qualitative studies with or without meta-synthesis	2 non-experimental studies	B	Fonseca et al. (2012) found that parents of infants with congenital anomalies experience a significant amount of psychological distress (p=0.003) and a prenatal diagnosis vs postnatal is associated with a higher psychological quality of life (p=0.045). Rychik et al. (2013) found that pregnant mothers of fetuses with congenital heart disease experience significant post-traumatic stress, depression, and anxiety.
Level IV · Opinion of respected authorities and/or reports of nationally recognized expert committees/consensus panels based on scientific evidence			
Level V · Evidence obtained from literature reviews, quality improvement, program evaluation, financial evaluation, or case reports · Opinion of nationally recognized expert(s) based on experiential evidence	1 QI	B	Davis et al. (2019) QI conducted over 40-month period in a tertiary pediatric medical center. Patients with single ventricle physiology provided with palliative care consult. Early palliative care consult allowed for more family and patient support starting at an earlier stage in life.
Recommendations Based on Evidence Synthesis: There is good and consistent evidence to support the practice change of early palliative care and family support for families of neonates with congenital heart disease to alleviate stress and anxiety.			

Appendix C

Reducing Stress and Anxiety among Families by Introducing Prenatal Palliative Care
 Page 1

DASS-21

Record ID _____

Today's Date _____

Date of Birth _____

Sex Female
 Male
 Prefer not answer

Please read each statement and choose the statement that best applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement.

	Did not apply to me at all	Applied to me to some degree, or some of the time	Applied to me to a considerable degree or a good part of time	Applied to me very much or most of the time
I found it hard to wind down	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was aware of dryness of my mouth	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I couldn't seem to experience any positive feeling at all	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I experienced breathing difficulty (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found it difficult to work up the initiative to do things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I tended to over-react to situations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I experienced trembling (e.g. in the hands)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I was using a lot of nervous energy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried about situations in which I might panic and make a fool of myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I had nothing to look forward to	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I found myself getting agitated	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found it difficult to relax	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt down-hearted and blue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was intolerant of anything that kept me from getting on with what I was doing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt I was close to panic	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was unable to become enthusiastic about anything	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt I wasn't worth much as a person	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I was rather touchy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was aware of the action of my heart in the absence of physical exertion (e.g. sense of heart rate increase, heart missing a beat)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt scared without any good reason	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that life was meaningless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Appendix D

Reducing Stress and Anxiety among Families by Introducing Prenatal Palliative Care
 Page 1

Brief COPE

Record ID _____

Today's Date _____

Sex Female
 Male
 Prefer not to answer

Date of Birth _____

The following items deal with ways you've been coping with the stress in your life. Make your answers as true FOR YOU as you can.

	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
I've been turning to work or other activities to take my mind off things.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been concentrating my efforts on doing something about the situation I'm in.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been saying to myself "this isn't real."	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been using alcohol or other drugs to make myself feel better.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been getting emotional support from others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been giving up trying to deal with it.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been taking action to try to make the situation better.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been refusing to believe that it has happened.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been saying things to let my unpleasant feelings escape.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been getting help and advice from other people.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The following items deal with ways you've been coping with the stress in your life. Make your answers as true FOR YOU as you can.

	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
I've been using alcohol or other drugs to help me get through it.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been trying to see it in a different light, to make it seem more positive.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been criticizing myself.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been trying to come up with a strategy about what to do.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been getting comfort and understanding from someone.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been giving up the attempt to cope.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been looking for something good in what is happening.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been making jokes about it.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been accepting the reality of the fact that it has happened.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The following items deal with ways you've been coping with the stress in your life. Make your answers as true FOR YOU as you can.

	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
I've been expressing my negative feelings.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been trying to find comfort in my religion or spiritual beliefs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been trying to get advice or help from other people about what to do.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been learning to live with it.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been thinking hard about what steps to take.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I've been blaming myself for things that happened.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been praying or meditating.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been making fun of the situation.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Appendix E

Reducing Stress and Anxiety among Families by Introducing Prenatal Palliative Care
 Page 1

Data Collection Tool

Record ID _____

Was the patient referred for palliative care consult? Yes
 No

Does the patient meet criteria for palliative care consult? Yes
 No

Did the patient complete pre-consult survey? Yes
 No

Was the palliative care consult completed? Yes
 No

Did the patient complete the post-consult survey? Yes
 No