

Christine Campbell MP



State Member for Pascoe Vale

Electorate Office: 416A Bell Street Pascoe Vale VIC 3044

Phone: 03 9354 9935

C/o Committee Secretary

Senate Standing Committee on Community Affairs

Parliament House

CANBERRA ACT 2600

Australia

Email: community.affairs.sen@aph.gov.au

Dear Senators,

PROVISION OF PALLIATIVE CARE IN AUSTRALIA SPECIFICALLY ADDRESSING PERINATAL PALLIATIVE CARE

Perinatal palliative care is a system of interdisciplinary “care to prevent and relieve infant suffering and improve the conditions of the infant’s living and dying. It is a team approach to relieving physical, psychological, social, emotional, and spiritual suffering of the dying infant and the family.”¹ Perinatal palliative care offers positive therapeutic actions that are the opposite of ‘doing nothing’ and provides comfort therapies that are essential for the precious time with their newborn.

Prenatal testing, both invasive and non-invasive, is routine during a woman’s pregnancy to monitor the health of her developing child in utero. Women and their partners who receive a prognosis that their child has a life-limiting abnormality need to be given support in order to come to terms with this situation. Australia does not currently have specially designated perinatal palliative care units in all major maternity hospitals. The available technology in prenatal testing has resulted in the diagnosis of life-limiting conditions of the developing child. Following the identification of a condition of foetal abnormality, the woman and her family need to be given the time and support to make informed decisions for the child and have access to evidence-based medical care for the child and support from healthcare professionals and community services for the parent/s.

Infants from 0-28 days with a life-threatening condition require special consideration because the circumstances of their illness and death may be different from other children with a life-threatening condition. In neonatal intensive care units, there is often little time for parents to spend with the child before death, particularly if the mother is physically recovering from a difficult birth.²

¹ Anita Catlin and Brian Carter, “Creation of a Neonatal End-of-Life Palliative care Protocol,” in *Journal of Perinatology*, 2002, 22: 184-195, 184, <http://dav.sonoma.edu/users/c/catlin/NICUPalliativeCare.pdf> accessed 7 March, 2012; Australian College of Neonatal Nurses, *Palliative Care and Neonatal Nursery Guidelines for neonatal nurses in Australia*, 2010, <http://www.acnm.org.au/LinkClick.aspx?fileticket=-8MryR4waKA%3D&tabid=75> accessed 9 March 2012.

² Victorian Government, *Strengthening care for children with a life-threatening condition*, 2008-2015, (Melbourne: Metropolitan Health and Aged care Services Division, 2008), 21; B. Carter, C. Hubble and K. Weise, “Palliative Medicine in Neonatal and Pediatric Intensive Care,” in *Child and Adolescent Psychiatric Clinics of North America*, K, 2006. vol. 15, 2006: 759-777; T. Moro, K. Kavanaugh, S. Okuno-Jones, and J. VanKleef, “Neonatal end-of-life care. A review of the research literature,” *Journal of Perinatal & Neonatal Nursing*, vol. 20, 2006: 262-272; L. Cook, and J. Watchko, “Decision making for the critically ill neonate near the end of life,” *Journal of Perinatology*, vol. 16, 1996: 133-136; S. Wall, and J. Partridge, “Death in the intensive care nursery: physician practice of withdrawing and withholding life support,” *Pediatrics*, vol. 99, 1997: 64-70; L. Singh, J. Lantos, and W. Meadow, “End-of-life after birth: death and dying in a neonatal intensive care nursery,” *Pediatrics*, vol. 114, 2004: 1620-1626.

PERINATAL PALLIATIVE CARE: DEFINITIONAL ISSUES

In the broad sense palliative care is the comprehensive management of physical, psychological, social, spiritual, and existential needs for those with a life-limiting illness. Palliative care is defined by the World Health Organisation (WHO) as “an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.”³ The WHO definition further explains that Palliative Care provides relief from pain, neither hastens nor prolongs death, integrates the psychological and spiritual needs of the patient, offers support for the patient, and assists the family to cope during the illness and in their bereavement.⁴

The Palliative Care Australia (PCA) definition is not broad enough to encompass the complexity of the necessary care and support that is integral to palliative care: “Palliative care is specialist care provided for all people living with, and dying from a terminal condition and for whom the primary goal is quality of life.”⁵

The PCA definition focuses only on an outcome and is not primarily centred on the needs of the infant, the family, and the multidisciplinary team that supports the newborn and family in the community. Instead, the WHO definition, which is also included in *Supporting Australians to Live Well at the End of Life*, is a far more holistic definition of palliative care.⁶ Therefore the Senate Committee should think holistically, not outcome based, when considering palliative care.

Australia should be aiming to provide perinatal palliative care that focuses on the enhancement of the quality of life for the child, support for the family, and also includes the management of symptoms and provision for respite and care through death and bereavement for the family.⁷

The World Health Organisation (WHO) definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- *provides relief from pain and other distressing symptoms;*
- *affirms life and regards dying as a normal process;*
- *intends neither to hasten or postpone death;*
- *integrates the psychological and spiritual aspects of patient care;*
- *offers a support system to help patients live as actively as possible until death;*
- *offers a support system to help the family cope during the patients illness and in their own bereavement;*
- *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;*
- *will enhance quality of life, and may also positively influence the course of illness;*
- *is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.*

³ World Health Organisation, <http://www.who.int/cancer/palliative/definition/en> accessed 3 March 2012.

⁴ World Health Organisation, <http://www.who.int/cancer/palliative/definition/en> accessed 3 March 2012.

⁵ Palliative Care Australia, <http://www.palliativecare.org.au/Default.aspx?tabid=1940> accessed 3 March 2012.

⁶ National Palliative Care Strategy 2010, *Supporting Australians to Live Well at the End of Life*, [http://www.health.gov.au/internet/main/publishing.nsf/Content/533C02453771A951CA256F190013683B/\\$File/NationalPalliativeCareStrategy.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/533C02453771A951CA256F190013683B/$File/NationalPalliativeCareStrategy.pdf) accessed 5 March 2012.

⁷ S.R. Leuthner, “Fetal Palliative Care,” in *Clin Perinatol*, vol. 31, 2004: 649-665.

The WHO Definition of Palliative Care for Children

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- *Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.*
- *It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.*
- *Health providers must evaluate and alleviate a child's physical, psychological, and social distress.*
- *Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.*
- *It can be provided in tertiary care facilities, in community health centres and even in children's homes.⁸*

Recommendation 1: That the WHO definition of palliative care be adopted by the Committee because it specifically includes palliative care for children of which perinatal palliative care is a specialised area.

⁸ World Health Organisation, <http://www.who.int/cancer/palliative/definition/en> accessed 3 March 2012.

WHY PERINATAL PALLIATIVE CARE NEEDS TO BE SPECIFICALLY ADDRESSED BY THE SENATE INQUIRY

Due to the fact that many of these infants live for a very short period of time, sometimes minutes, hours or a few days, it is crucial to provide measures that ensure that the time with parent/s and family is as supportive as humanly possible. It is reasonable to expect that the newborn and their family, at a time of significant life crisis, receive perinatal palliative care which provides appropriate medical care for the infant because of their life-limiting condition and comfort, compassion and support for the whole family.

To my knowledge, there are no specially designated perinatal palliative care units in Australian maternity hospitals, and there is no accompanying outreach program for regional hospitals. Unfortunately, some studies have shown that in many cases families experience insensitivity, discontinuity and unnecessary suffering at the time of the death of a newborn child.⁹ Maternity and regional hospitals need to include a perinatal palliative care program with a full range of services and links to other community organisations in order to prevent gaps that can leave families isolated in their grief and loss.

The time families have to spend with their child is precious, especially when parents have not had time to plan for a very limited lifespan for their daughter or son. Health professionals need to be ready to guide parents through this distressing period in their life and the life of their child. Parent/s need to be able to make decisions about the care their child receives because the time while the child lives can contain meaningful expressions of love, nurturing and support which respects the dignity and needs of the child and assists the parents and family in the healing process after the child's death. Many of these options are simply an extension of what is presently good palliative care practice and needs to be offered to parent/s and families because it values the life of the child and allows for parenting, however short, to take place.¹⁰

The Victorian Government initiative *Strengthening care for children with a life-threatening condition* states "all Victorian children with a life-threatening condition and their families will receive high quality care which is delivered in a timely and coordinated way in the best interests of the child."¹¹ Provision for caring for children around the time of birth and providing support for the child's parent/s is an integral part of palliative care services. However, even though this is in the policy document, what is stated needs to be implemented in practice, especially in Maternity hospitals.

Recommendation 2: That the Senate Committee specifically address perinatal palliative care.

Recommendation 3: At a minimum, perinatal palliative care should be provided in every teaching maternity hospital in Australia.

⁹ Medscape Nurses, "Palliative Care and Neonatal Loss," 2004, <http://www.medscape.org/viewarticle/494959> accessed 6 March 2012.

¹⁰ S. Leuthner and E.L. Jones, "Fetal Concerns Program, A Model for Palliative Care," in *American Journal of of Maternal Child Nursing*, vol. 32, 2007, 272-278; Leuthner, "Fetal Palliative Care," 649-665.

¹¹ Victorian Government, *Strengthening care for children with a life-threatening condition*, 2008-2015, 2.

SENATE TERMS OF REFERENCE

(a) The factors influencing access to and choice of appropriate palliative care that meets the needs of the population, including:

- i. people living in rural and regional areas,*
- ii. indigenous people,*
- iii. people from culturally and linguistically diverse backgrounds,*
- iv. people with disabilities, and*
- v. children and adolescents.*

There is not enough appropriate palliative care available to cover the population in (i)-(iv). Access to palliative care services needs to be increased in all areas to meet the needs of those in the community at every stage of life including the support and funding to provide adequate services for all members of the community in large cities and regional centres. Furthermore, the concern is that perinatal palliative care has not been sufficiently included in the factors influencing access to and choice of palliative care that meets the needs of the population.

It is not always in the best interests of the child or family for the mother to be separated from the child or to transfer the child with a life-limiting illness to another hospital. Transfer is traumatic and expensive. Parents already have access to support systems in the local community and are familiar with health care providers and spiritual/religious support in their local community.

The availability of specialists, such as neonatologists, geneticists, or neurologists, to make certain the diagnosis is correct should be provided in regional community hospitals. Provision needs to be made for the development and use of telemedicine, and tele-health technologies between community centres and regional referral centres and major hospitals to share expertise and specialists located in major maternity hospitals.

Regional hospitals need to have in place a perinatal palliative care protocol and staff trained in perinatal palliative care with other larger providers of this service. A collegial relationship between regional hospitals and major maternity hospitals is essential to ensure additional and ongoing training of staff and the resources to manage the care of the dying infant and support the family throughout this time of crisis.¹²

Sections (i) to (v) need further attention in order to provide adequate palliative care in each State and Territory. I defer to those with specific expertise in this area.

Recommendation 4: That Section (a), (v) confirms the value of palliative care for infants with terminal conditions from pre-natal to birth.¹³

(b) The funding arrangements for palliative care provision, including the manner in which sub-acute funding is provided and spent.

At present there is insufficient funding allocated by the States and Territories to adequately meet the needs of those requiring palliative care. Since perinatal palliative care has such limited numbers of newborns at any one time in a hospital, in order to provide effective care and support, as a general rule, funding should be prioritised to physicians, nurses, other health care professionals and volunteers who care for the newborn and their family: mother, father, siblings and extended family. Administration funding should be a secondary focus.

Recommendation 5: Perinatal palliative care funding to be specifically provided for the education and training of staff and volunteers in hospitals.

¹² Catlin and Carter, "Creation of a Neonatal End-of-Life Palliative Care Protocol," 186.

¹³ National Perinatal Association, 2009, <http://www.nationalperinatal.org/advocacy/pdf/Palliative-Care.pdf> accessed 7 March, 2012.

(c) the efficient use of palliative, health and aged care resources

The model exists in some countries for perinatal palliative care that provides support which is patient-centred medical care and psychological support from the time of diagnosis to beyond the child's death. This type of program provides opportunities for parents to make decisions concerning care and access support – medical, psychological and spiritual for the unborn child and for themselves. A perinatal palliative care program allows parents to engage with their pregnancy and make appropriate plans for the birth and the likely death of their infant. This provides the opportunity for precious memories of loving, nurturing, and parenting.¹⁴

In the USA, usually within obstetric hospitals, there exists a multidisciplinary team that may include physicians, obstetricians, midwives, social workers, genetic counsellors, neonatologists, psychologists, chaplains and other relevant specialists. These provide the mechanism to tap into organisations that support parents who have at some stage experienced these unfortunate circumstances.

Recommendation 6: That perinatal palliative care be provided in maternity and in regional hospitals via shared expertise using telemedicine facilities which are cost effective and efficient.

(d) The effectiveness of a range of palliative care arrangements, including hospital care, residential or community care and aged care facilities

Options that could be included in the effectiveness of palliative care arrangements is provision for mentor families to communicate with parents who have been given a similar prenatal diagnosis. Parents should be given the opportunity to prepare for the birth and premature death of their child. This includes encouraging families to make plans before the baby is born and allowing parent/s the appropriate length of time to be able to make informed decisions. Mothers and families need time to inform other family members and arrange for the support that is needed. Time is also needed for hospital staff to make adequate preparation to devise a plan of care for the infant with a life-limiting condition. The intention is to care for and support the child and provide assistance for the parent/s at a time of crisis and the impending death of their child.

Recommendation 7: Where circumstances allow, parents to be sensitively informed as to what to expect and encouraged to participate in the living and dying process of their infant and are able to do so in a meaningful manner that respects the dignity of the child and their parenthood.¹⁵

¹⁴ David Munson and Steven R. Leuthner, "Palliative Care for the Family Carrying a Fetus with a Life-Limiting Diagnosis," in *Pediatric Clinics of North America*, vol. 54 (2007), 787-798,792; N. Hoeldtke and B. Calhoun, "Perinatal hospice," *American Journal of Obstetrics and Gynecology*, vol 185, 2001525-529.

¹⁵ Catlin and Carter, "Creation of a Neonatal End-of-Life Palliative Care Protocol," 185-194; National Perinatal Association, 2009, <http://www.nationalperinatal.org/advocacy/pdf/Palliative-Care.pdf> accessed 7 March, 2012.

Perinatal palliative care arrangements that can make a difference to families include:

- Providing information to parent/s about the options available and the support services for the child and family;
- A Planning Group (potential involvement of: medical staff – obstetrics/gynaecology/neonatology, nursing, midwifery, labour and delivery, postpartum, nurseries, child health specialists, developmental experts, case management, hospice, social services, ethics and chaplain programs) who are available to educate other members of staff and work with parent/s and families;
- Having appropriate medical staff at the delivery to confirm diagnosis;
- Long-term prognosis for newborns with severe disabilities because there is no certainty as to the time of death;
- Palliative care training from palliative care/hospice experts;
- Priority assessment and access to palliative care considering that the child's life may be measured in hours, days or weeks;
- Access guidelines to ensure that perinatal palliative care is initiated in a timely manner;
- Familiarity with pain assessment tools for use with newborns;
- Staff with knowledge/experience in crisis intervention, grief stages, family dynamics, and stress and coping mechanisms; and a
- A plan for facilitated conflict mediation should be in place prior to hospitals initiating a palliative care program.¹⁶

Perinatal palliative care is child-centred and involves the parent/s and family and healthcare professionals in the care and support for the child in a life-limiting illness by:

- Offering parent/s choices and discussing options;
- Assisting parent/s to draw up a birth plan consistent with their culture and values;
- Individualised treatment plan of care agreed by the parents and the medical team that aims to optimise outcomes including psychological ones for the whole family;
- Medical support and counselling for the woman who carries her child to term knowing that the child has a life-limiting condition;
- Staff recognition of mother's immediate postpartum needs if she has recently given birth;
- Recognition of the needs of the father of the child and his support for the child's mother;
- Framework for legal, clinical and ethical practice in these circumstances;
- Being sensitive to the location of perinatal palliative care facilities in hospitals;
- The provision of a room for privacy in a specially designated home-like setting, large enough to hold extended family and where a spiritual service can be held. This area should also include access to the use of a camera, hospital chapel, library with books on grieving and a journal for parents to write about their child could be of assistance;¹⁷
- Continuity between areas of care, especially considering changes of shift;
- Calling the baby by name;
- Offering to contact support services when required (pastoral care, chaplain, clergy, social worker, friend, and/or specific organisation in grief counselling);
- Options for the preserving of keepsakes, etc., that assist with memory making for the family;
- An information pack provided to parent/s after the infant dies about grieving; and
- A plan for staff to review perinatal palliative care options and management.¹⁸

¹⁶ Catlin and Carter, "Creation of a Neonatal End-of-Life Palliative Care Protocol," 185-194; National Perinatal Association, 2009, <http://www.nationalperinatal.org/advocacy/pdf/Palliative-Care.pdf> accessed 7 March, 2012; Medscape Nurses, "Palliative Care and Neonatal Loss," 2004, <http://www.medscape.org/viewarticle/494959> accessed 6 March 2012, 3; Munson and Leuthner, "Palliative Care for the family Carrying a Fetus with a Life-Limiting Diagnosis," 792, 794.

¹⁷ Kain, Developing Palliative Care Models in Palliative Care Nursing: An investigation of parameters and barriers for practice, 2007, http://eprints.qut.edu.au/17012/1/Victoria_J._Kain_Thesis.pdf accessed 3 March 2012, 167.

¹⁸ Catlin and Carter, "Creation of a Neonatal End-of-Life Palliative Care Protocol," 185-194; National Perinatal Association, 2009, <http://www.nationalperinatal.org/advocacy/pdf/Palliative-Care.pdf> accessed 7 March, 2012.

(e) The composition of the palliative care workforce, including:

- i. *its ability to meet the needs of the ageing population, and*
- ii. *the adequacy of workforce education and training arrangements.*

There is a need for training in pediatric palliative care through specialised courses in neonatal and perinatal medicine - for doctors, nurses and other healthcare professionals.

Specialist perinatal palliative care services can provide advice and secondary consultation to staff working in neonatal units to support them in meeting the physical needs of the child and the grief and bereavement needs of the parent/s.

The role of perinatal palliative care services is to also provide education, training and support for staff such as radiologists and midwives who conduct screening who can assist them in communicating and supporting parents if a life-limiting condition is diagnosed.¹⁹

Recommendation 8: That the palliative care workforce have specific education and training to meet the needs of children in utero and newborns with a life-limiting condition.

(f) The adequacy of standards that apply to the provision of palliative care and the application of the Standards for Providing Quality Care to All Australians.

The provision of standards and the application of quality care are important in perinatal palliative care given that time is short because of the life-limiting condition of the child.

In cases where perinatal palliative care is needed for a newborn, the reality is that families may have siblings that may create additional problems of childcare while one or both parents are in the hospital with their newborn.

Recommendation 9: That there be protocols for perinatal palliative care in maternity and regional hospitals which includes consideration of childcare needs of families.

(g) Advance care planning, including:

- i. *avenues for individuals and carers to communicate with health care professionals about end-of-life care,*
- ii. *national consistency in law and policy supporting advance care plans, and*
- iii. *scope for including advance care plans in personal electronic health records;*

Recommendation 10: That written information be provided to assist parents and that this be accompanied by support services for parents of unborn and newborns with a life-limiting condition.²⁰

Perinatal palliative care is offered in other countries such as the USA and the UK. A perinatal palliative care protocol has been developed and has been implemented in hospitals in America.²¹ There are lessons to be learnt from overseas provisions of perinatal palliative care.

Recommendation 11: Australia needs to ensure that all children and their families receive competent care and support at the end of life.²²

¹⁹ Victorian Government, Strengthening care for children with a life-threatening condition, 2008-2015, 21.

²⁰ Munson and Leuthner, "Palliative Care for the Family Carrying a Fetus with a Life-Limiting Diagnosis," 794; Leuthner, "Fetal Palliative Care," 661-663.

²¹ Catlin and Carter, "Creation of a Neonatal End-of-Life Palliative care Protocol," has an extensive and comprehensive coverage of the care and support for the infant, the family and healthcare professionals in major and regional hospitals, 184-195.

²² M.A. Shah and D. Campbell, Eds., *Transcultural Aspects of Perinatal Health Care: A Resource Guide*, American Academy of Pediatrics, 2004.

(h) The availability and funding of research, information and data about palliative care needs in Australia.

Unfortunately, perinatal palliative care does not exist throughout Australia. However, it was recognised from two studies in Victoria by the relevant health care professionals and pregnant women that a perinatal palliative care program would be of benefit.²³

Further research needs to be initiated and health care professionals need to be engaged in the research and consultation process for the implementation of perinatal palliative care. Leuthner states that “efforts in advance palliative care planning for the fetus at risk of dying are as meaningful and should be as clinically and socially acceptable as the provision of continued life-extending endeavours.”²⁴

The consequence of pre-natal testing calls for an ethical imperative to ensure parents who receive the diagnosis of foetal abnormality during the pregnancy are given the opportunity to make informed choices and are presented with appropriate options which includes perinatal palliative care and the access to evidence-based, patient centred support for their child, the parent/s and the family.

Recommendation 12: Funding to establish perinatal palliative care in major maternity hospitals and outreach programs for regional hospitals and support services for women and parents, including the appropriate training for healthcare professionals and volunteers.

Thank you for the consideration of my submission.

Hon. Christine Campbell
Member for Pascoe Vale

²³ A. Horwood, S. Buscombe, J. Hodgson “Perinatal Hospice Care,” Unpublished Masters Dissertation, University of Melbourne, 2009.

²⁴ Leuthner, “Fetal Palliative Care,” 661.

In summary, the recommendations for the provision of palliative care in Australia are:

Recommendation 1: That the WHO definition of palliative care be adopted by the Committee because it specifically includes palliative care for children of which perinatal palliative care is a specialised area.

Recommendation 2: That the Senate Committee specifically address perinatal palliative care.

Recommendation 3: At a minimum, perinatal palliative care should be provided in every teaching maternity hospital in Australia.

Recommendation 4: In Section (a) (v), that there be confirmation of the value of palliative care for infants with terminal conditions from pre-natal to birth.²⁵

Recommendation 5: In Section (b), that perinatal palliative care funding be specifically provided for the education and training of staff and volunteers in hospitals.

Recommendation 6: In section (c), that perinatal palliative care be provided in maternity and in regional hospitals via shared expertise using telemedicine facilities which are cost effective and efficient.

Recommendation 7: In section (d), that where circumstances allow, parents to be sensitively informed as to what to expect and encouraged to participate in the living and dying process of their infant and are able to do so in a meaningful manner that respects the dignity of the child and their parenthood.²⁶

Recommendation 8: In section (e) (ii), that the palliative care workforce have specific education and training to meet the needs of children in utero and newborns with a life-limiting condition.

Recommendation 9: In section (f), that there be protocols for perinatal palliative care in maternity and regional hospitals which includes consideration of childcare needs of families.

Recommendation 10: In section (g) (i), that written information be provided to assist parents and that this be accompanied by support services for parents of unborn and newborns with a life-limiting condition.²⁷

Recommendation 11: In section (g), Australia needs to ensure that all children and their families receive competent care and support at the end of life.²⁸

Recommendation 12: In section (h) that there be funding to establish perinatal palliative care in major maternity hospitals and outreach programs for regional hospitals and support services for women and parents, including the appropriate training for healthcare professionals and volunteers.

²⁵ National Perinatal Association, 2009, <http://www.nationalperinatal.org/advocacy/pdf/Palliative-Care.pdf> accessed 7 March, 2012.

²⁶ Catlin and Carter, "Creation of a Neonatal End-of-Life Palliative Care Protocol," 185-194; National Perinatal Association, 2009, <http://www.nationalperinatal.org/advocacy/pdf/Palliative-Care.pdf> accessed 7 March, 2012.

²⁷ Munson and Leuthner, "Palliative Care for the Family Carrying a Fetus with a Life-Limiting Diagnosis," 794

²⁸ M.A. Shah and D. Campbell, Eds., *Transcultural Aspects of Perinatal Health Care: A Resource Guide*, American Academy of Pediatrics, 2004.