

Leitsätze für Palliativversorgung und Trauerbegleitung in der Peri- und Neonatologie

Literaturverzeichnis und weiterführende Literatur

Publikationen

- AVELIN, P., RADESTAD, I., SAFLUND, K., WREDLING, R. & ERLANDSSON, K. 2013. Parental grief and relationships after the loss of a stillborn baby. *Midwifery*, 29, 668-73.
- BENDER 2003a. Schwangerschaftsabbruch nach Pränataldiagnostik. <https://www.aerzteblatt.de/down.asp?id=1136>: Deutsche Gesellschaft für Gynäkologie und Geburtshilfe.
- BUNDESÄRZTEKAMMER 2011. Grundsätze der Bundesärztekammer zur ärztlichen Sterbebegleitung. *Deutsches Ärzteblatt*, 108.
- BREEZE, A. C., LEES, C. C., KUMAR, A., MISSFELDER-LOBOS, H. H. & MURDOCH, E. M. 2007. Palliative care for prenatally diagnosed lethal fetal abnormality. *Arch Dis Child Fetal Neonatal Ed*, 92, F56-8.
- CAEYMAEX, L., SPERANZA, M., VASILESCU, C., DANAN, C., BOURRAT, M. M., GAREL, M. & JOUSSELME, C. 2011. Living with a crucial decision: a qualitative study of parental narratives three years after the loss of their newborn in the NICU. *PLoS One*, 6, e28633.
- CALHOUN, B. C., NAPOLITANO, P., TERRY, M., BUSSEY, C. & HOELDTKE, N. J. 2003. Perinatal hospice. Comprehensive care for the family of the fetus with a lethal condition. *J Reprod Med*, 48, 343-8.
- CAPITULO, K. L. 2005. Evidence for healing interventions with perinatal bereavement. *MCN Am J Matern Child Nurs*, 30, 389-96.
- CATLIN, A. & CARTER, B. 2002. Creation of a neonatal end-of-life palliative care protocol. *J Perinatol*, 22, 184-95.
- CHITTY LS, BARNES CA, BERRY C. Continuing with pregnancy after a diagnosis of lethal abnormality: experience of five couples and recommendations for management. *BMJ (Clinical research ed.)*. 1996;313(7055):478-480.
- COPE, H., GARRETT, M. E., GREGORY, S. & ASHLEY-KOCH, A. 2015. Pregnancy continuation and organizational religious activity following prenatal diagnosis of a lethal fetal defect are associated with improved psychological outcome. *Prenat Diagn*, 35, 761-8.
- CÔTÉ-ARSENAULT, D. & DENNEY-KOELSCH, E. 2011. "My baby is a person": parents' experiences with life-threatening fetal diagnosis. *J Palliat Med*, 14, 1302-8.
- CÔTÉ-ARSENAULT, D., KROWCHUK, H., HALL, W. J., & DENNEY-KOELSCH, E. 2015. We want what's best for our baby: Prenatal Parenting of Babies with Lethal Conditions. *J Prenat Perinat Psychol Health*.
- CÔTÉ-ARSENAULT, D. & DENNEY-KOELSCH, E. 2016. "Have no regrets:" Parents' experiences and developmental tasks in pregnancy with a lethal fetal diagnosis. *Soc Sci Med*, 154, 100-9.
- CRAIG, F., ABU-SAAD HUIJER, H., BENINI, F., KUTTNER, L., WOOD, C., FERARIS, P. C. & ZERNIKOW, B. 2007. IMPaCCT standards for pediatric palliative care. <http://www.eapcnet.eu/?TabId=284>: Steering Committee of the EAPC task force on palliative care for children and adolescents
- CRAIG, F., ABU-SAAD HUIJER, H., BENINI, F., KUTTNER, L., WOOD, C., FERARIS, P. C. & ZERNIKOW, B. 2008. [IMPaCCT: standards of paediatric palliative care]. *Schmerz*, 22, 401-8.
- DAVIES, R. 2004. New understandings of parental grief: literature review. *J Adv Nurs*, 46, 506-13.
- DABOVAL, T. & SHIDLER, S. 2014. Ethical framework for shared decision making in the neonatal intensive care unit: Communicative ethics. *Paediatr Child Health*, 19, 302-4.
- EINAUDI, M. A., LE COZ, P., MALZAC, P., MICHEL, F., D'ERCOLE, C. & GIRE, C. 2010. Parental experience following perinatal death: exploring the issues to make progress. *Eur J Obstet Gynecol Reprod Biol*, 151, 143-8.
- GARTEN, L., GLOCKNER, S., SIEDENTOPF, J. P. & BUHRER, C. 2015. Primary palliative care in the delivery room: patients' and medical personnel's perspectives. *J Perinatol*, 35, 1000-5.
- GUON, J., WILFOND, B. S., FARLOW, B., BRAZG, T. & JANVIER, A. 2014. Our children are not a diagnosis: the experience of parents who continue their pregnancy after a prenatal diagnosis of trisomy 13 or 18. *Am J Med Genet A*, 164A, 308-18.
- HEIDER, U., STEGER, F. 2014. Individuelle Entscheidungsfindung nach pränatal diagnostizierter schwerer fetaler Fehlbildung. *Ethik Med*, 26: 269 - 285.
- HOELDTKE, N. J. & CALHOUN, B. C. 2001. Perinatal hospice. *Am J Obstet Gynecol*, 185, 525-9.

- JANVIER, A., FARLOW, B. & BARRINGTON, K. J. 2016. Parental hopes, interventions, and survival of neonates with trisomy 13 and trisomy 18. *Am J Med Genet C Semin Med Genet*, 172, 279-87.
- JANVIER, A., FARLOW, B. & WILFOND, B. S. 2012. The experience of families with children with trisomy 13 and 18 in social networks. *Pediatrics*, 130, 293-8.
- JOHNSTON, T. A., SIDEBOTHAM, M. & SANDS, J. 2005. Neonatal death following termination of pregnancy. *BJOG*, 112, 1159-62.
- KAVANAUGH, K. & MORO, T. 2006. Supporting parents after stillbirth or newborn death: There is much that nurses can do. *Am J Nurs*, 106, 74-9.
- LATHROP, A. & VANDEVUSSE, L. 2011. Affirming motherhood: validation and invalidation in women's perinatal hospice narratives. *Birth*, 38, 256-65.
- LEUTHNER, S. & JONES, E. L. 2007. Fetal Concerns Program: a model for perinatal palliative care. *MCN Am J Matern Child Nurs*, 32, 272-8.
- LLOYD, J. & LAURENCE, K. M. 1985. Sequelae and support after termination of pregnancy for fetal malformation. *Br Med J (Clin Res Ed)*, 290, 907-9.
- LUMLEY, J. 1990. Through a glass darkly: ultrasound and prenatal bonding. *Birth*, 17, 214-7.
- MARTEAU, T., DRAKE, H. & BOBROW, M. 1994. Counselling following diagnosis of a fetal abnormality: the differing approaches of obstetricians, clinical geneticists, and genetic nurses. *J Med Genet*, 31, 864-7.
- MILSTEIN, J. 2005. A paradigm of integrative care: healing with curing throughout life, "being with" and "doing to". *J Perinatol*, 25, 563-8.
- MUNSON D, LEUTHNER SR. Palliative care for the family carrying a fetus with a life-limiting diagnosis. *Pediatric clinics of North America*. 2007;54(5):787-798, xii. Nelson KE, Hexem KR, Feudtner C. Inpatient hospital care of children with trisomy 13 and trisomy 18 in the United States. *Pediatrics*. 2012;129(5):869-876.
- PEABODY, J. L. & MARTIN, G. I. 1996. From how small is too small to how much is too much. Ethical issues at the limits of neonatal viability. *Clin Perinatol*, 23, 473-89.
- REDLINGER-GROSSE, K., BERNHARDT, B. A., BERG, K., MUENKE, M. & BIESECKER, B. B. 2002. The decision to continue: the experiences and needs of parents who receive a prenatal diagnosis of holoprosencephaly. *Am J Med Genet*, 112, 369-78.
- ROCHA CATANIA, T., STEIN BERNARDES, L., GUERRA BENUTE, G. R., BENTO CICARONI GIBELI, M. A., BERTOLASSI DO NASCIMENTO, N., APARECIDA BARBOSA, T. V., JORNADA KREBS, V. L. & FRANCISCO, R. P. V. 2017. When One Knows a Fetus Is Expected to Die: Palliative Care in the Context of Prenatal Diagnosis of Fetal Malformations. *J Palliat Med*, 20, 1020-1031.
- SAUNDERS, C. 1969. The management of fatal illness in childhood. *Proc R Soc Med*, 62, 550-3.
- STEVEN J. RALSTON, M., STEVEN R. LEUTHNER, M., AMERICAN COLLEGE OF OBSTETRICIANS, GYNECOLOGISTS, C. O. E. & AMERICAN ACADEMY OF PEDIATRICS, C. O. B. 2011. Maternal-fetal intervention and fetal care centers. *Pediatrics*, 128, e473-8.
- TOSELLO B, DANY L, GIRE C, ET AL. Perceptions of lethal fetal abnormality among perinatal professionals and the challenges of neonatal palliative care. *Journal of palliative medicine*. 2014;17(8):924-930.
- VADEYAR, S., JOHNSTON, T. A., SIDEBOTHAM, M. & SANDS, J. 2005. NEONATAL DEATH FOLLOWING TERMINATION OF PREGNANCY. *BJOG*, 112, 1159-62.
- VAN MECHELEN, W., AERTGEERTS, B., DE CEULAER, K., THOONSEN, B., VERMANDERE, M., WARMENHOVEN, F., VAN RIJSWIJK, E. & DE LEPELEIRE, J. 2013. Defining the palliative care patient: a systematic review. *Palliat Med*, 27, 197-208.
- WALKER, L. V., MILLER, V. J. & DALTON, V. K. 2008. The health-care experiences of families given the prenatal diagnosis of trisomy 18. *J Perinatol*, 28, 12-9.
- WHITFIELD, J. M., SIEGEL, R. E., GLICKEN, A. D., HARMON, R. J., POWERS, L. K. & GOLDSON, E. J. 1982. The application of hospice concepts to neonatal care. *Am J Dis Child*, 136, 421-4.
- WIDGER K, PICOT C. Parents' perceptions of the quality of pediatric and perinatal end-of-life care. *Pediatric nursing*. 2008;34(1):53-58.
- WOOL, C. 2011. Systematic review of the literature: parental outcomes after diagnosis of fetal anomaly. *Adv Neonatal Care*, 11, 182-92.

- WOOL, C., REPKE, J. T. & WOODS, A. B. 2016. Parent reported outcomes of quality care and satisfaction in the context of a life-limiting fetal diagnosis. *J Matern Fetal Neonatal Med*, 1-6.
- WORLD HEALTH ORGANIZATION [WHO]. Definition of Palliative Care [Online]. Available: <http://www.who.int/cancer/palliative/definition/en/> [Accessed 10.01.2015].
- YOON, J. D., RASINSKI, K. A. & CURLIN, F. A. 2010. Moral controversy, directive counsel, and the doctor's role: findings from a national survey of obstetrician-gynecologists. *Acad Med*, 85, 1475-81.3

Bücher zum Thema Spiritualität und Seelsorge

- Erhard Weiher, *Das Geheimnis des Lebens berühren – Spiritualität bei Krankheit, Sterben, Tod*, Stuttgart: Kohlhammer Verlag 42014
- Birgit Heller/Andreas Heller, *Spiritualität und Spiritual Care. Orientierungen und Impulse*, Bern: Verlag Hans Huber 2014.
- Kerstin Lammer et al, *Menschen stärken. Seelsorge in der evangelischen Kirche*, Gütersloh: Gütersloher Verlagshaus 2015
- Wilfried Sturm, *Was soll man denn da in Gottes Namen sagen? Der seelsorgerliche Umgang mit ethischen Konfliktsituationen im Bereich der Neonatologie und seine Bedeutung für das Verhältnis von Seelsorge und Ethik*, Göttingen: Verlag Vandenhoeck & Ruprecht 2015

Bücher zum Thema Team

- Monika Müller/ David Pfister (Hrsg.): *Wie viel Tod verträgt das Team? Belastungs- und Schutzfaktoren in Hospizarbeit und Palliativmedizin*, Vandenhoeck & Ruprecht Verlag, 3. Auflage, Göttingen, 2014

Bücher:

Palliativversorgung

- Lars Garten, Kerstin von der Hude, *Palliativversorgung und Trauerbegleitung in der Neonatologie*, Springer-Verlag, 2014
- Boris Zernikow, *Palliativversorgung von Kindern und Jugendlichen*, Springer Verlag, 2013
- Borasio, *Über das Sterben. Was wir wissen. Was wir tun können. Wie wir uns darauf einstellen*, dtv, 2014
- Hannah Lothrop, *Gute Hoffnung – Jähes Ende*, Kösel Verlag, 2016
- Carolin Erhardt-Seidl und Kathrin Fezer Schadt, *Weitertragen*, edition riedenburg, 2018

Trauer und Spiritualität

- Kerstin Lammer *Trauer verstehen*, Springer Verlag 2014
- Erhard Weiher, *Das Geheimnis des Lebens berühren – Spiritualität bei Krankheit, Sterben, Tod*, Stuttgart: Kohlhammer Verlag 42014
- Birgit Heller/Andreas Heller, *Spiritualität und Spiritual Care. Orientierungen und Impulse*, Bern: Verlag Hans Huber 2014.
- Kerstin Lammer et al, *Menschen stärken. Seelsorge in der evangelischen Kirche*, Gütersloh: Gütersloher Verlagshaus 2015
- Wilfried Sturm, *Was soll man denn da in Gottes Namen sagen? Der seelsorgerliche Umgang mit ethischen Konfliktsituationen im Bereich der Neonatologie und seine Bedeutung für das Verhältnis von Seelsorge und Ethik*, Göttingen: Verlag Vandenhoeck & Ruprecht 2015

Selbstsorge und Resilienz

- Christian Firus, *Verabredung mit dem Glück (Resilienz)*
- Monika Müller/ David Pfister (Hrsg.): *Wie viel Tod verträgt das Team? Belastungs- und Schutzfaktoren in Hospizarbeit und Palliativmedizin*, Vandenhoeck & Ruprecht Verlag, 3. Auflage, Göttingen, 2014
- Franziska Offermann: *Wenn Kollegen trauern*, Kösel-Verlag, 1. Auflage, München, 2016