Synopsis

International digest of children’s palliative care research abstracts

Editors: Dr Satbir Singh Jassal, Dr Susie Lapwood, Dr Linda Maynard, Sue Langley and Lizzie Chambers
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Together for Short Lives is a UK wide charity that, together with our members, speaks out for all children and young people who are expected to have short lives. Together with everyone who provides care and support to these children and families we are here to help them have as fulfilling lives as possible and the very best care at the end of life. We can't change the diagnosis, but we can help children and families make the most of their time together.

Together for Short Lives
New Bond House, Bond Street, Bristol, BS2 9AG
T: 0117 989 7820
E: info@togetherforshortlives.org.uk
www.togetherforshortlives.org.uk

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Dr Satbir Singh Jassal, Medical Director,
Rainbow’s Hospice for Children and Young People

Sue Langley, Library & Information Services Manager,
East Anglia’s Children’s Hospices (EACH)

Dr Linda Maynard, Nurse Consultant Children’s Palliative Care,
East Anglia’s Children’s Hospices (EACH)

Dr Susie Lapwood, Head of Research and Professional Development and Senior Specialty Doctor
Helen and Douglas House - Hospice care for children and young adults

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East Anglia’s Children’s Hospices (EACH) – New library and information service for children’s hospices

For staff working in children’s hospices it’s not always easy to access the most up-to-date resources to support professional and evidence based practice. However, the good news is that a new online library service is now available to all children’s hospices via the EACH library service.

The library has more than 3,000 resources, specialising in all aspects of caring for children and their families with life-limiting conditions. Library services and information can be provided over the telephone, by post or via email.

Services include:

- postal loans
- obtaining journal articles
- literature searching
- current awareness bulletin
- advice on accessing NHS electronic resources.

For more details about the long distance service visit www.each.org.uk/library

For information on membership, please contact: Sue Langley, Library and Information Services Manager sue.langley@each.org.uk; 01223 815103
Synopsis

Selected abstracts: November 2016 – June 2017

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Clinical & Ethical Decision Making


This document is the result of previous work carried out by different expert groups and submitted to multidisciplinary debate at a Conference about controversial, deficient, or new aspects in the field of neonatal palliative care, such as: 1) the deliberative decision-making process, 2) hospital and domiciliary palliative care, 3) donation after controlled cardiac death, and 4) moral stress in professionals. The most relevant conclusions were: the need to instruct professionals in bioethics and in the deliberative method to facilitate thorough and reasonable decision-making; the lack of development in the field of perinatal palliative care and domiciliary palliative care in hospitals that attend newborns; the need to provide neonatal units with resources that help train professionals in communication skills and in the management of moral distress, as well as delineate operational procedure and guidelines for neonatal organ donation.


OBJECTIVES: Surrogate decision makers involved in decisions to limit life support for an incapacitated patient in the ICU have high rates of adverse emotional health outcomes distinct from normal processes of grief and bereavement. Narrative self-disclosure (storytelling) reduces emotional distress after other traumatic experiences. We sought to assess the feasibility, acceptability, and tolerability of storytelling among bereaved surrogates involved in a decision to limit life support in the ICU. DESIGN: Pilot single-blind trial. SETTING: Five ICUs across three hospitals within a single health system between June 2013 and November 2014. SUBJECTS: Bereaved surrogates of ICU patients. INTERVENTIONS: Storytelling and control conditions involved printed bereavement materials and follow-up assessments. Storytelling involved a single 1- to 2-hour home or telephone visit by a trained interventionist who elicited the surrogate’s story. MEASUREMENTS AND MAIN RESULTS: The primary outcomes were feasibility (rates
of enrolment, intervention receipt, 3- and 6-mo follow-up), acceptability (closed and open-ended end-of-study feedback at 6 mo), and tolerability (acute mental health services referral). Of 53 eligible surrogates, 32 (60%) consented to treatment allocation. Surrogates' mean age was 55.5 (SD, 11.8), and they were making decisions for their parent (47%), spouse (28%), sibling (13%), child (3%), or other relation (8%). We allocated 14 to control and 18 to storytelling, 17 of 18 (94%) received storytelling, 14 of 14 (100%) and 13 of 14 (94%) control subjects and 16 of 18 (89%) and 17 of 18 (94%) storytelling subjects completed their 3- and 6-month telephone assessments. At 6 months, nine of 13 control participants (69%) and 16 of 17 storytelling subjects (94%) reported feeling "better" or "much better," and none felt "much worse." One control subject (8%) and one storytelling subject (6%) said that the study was burdensome, and one control subject (8%) wished they had not participated. No subjects required acute mental health services referral. CONCLUSION: A clinical trial of storytelling in this study population is feasible, acceptable, and tolerable.


PURPOSE: The death of a child is a devastating and tragic event for all those involved. This charter aims to help healthcare workers and people assisting terminally ill children to recognize some important rights of the child, with some related suggestions. We consider it important to have a trace of this process, based on the skillfulness of long-lasting experts. METHODS: In September 2012, a group of professionals working with children affected by incurable illness in Italy launched a project to formulate the charter. Trieste is the city where the group of professionals first met to start the project. The first step was a detailed literature search on the topic, the second step was an extensive discussion among the professionals (writing committee) to prepare a first draft; later (third step) the draft was revised by 38 experts in different areas, including patient and family representatives, and lastly (fourth step) the final version of the charter was prepared. RESULTS: We developed a document containing 10 rights and corresponding duties that could be applied to any clinical situation or circumstances and used as a guide by professionals and families caring for children in the terminal stages of an illness. CONCLUSIONS: The Trieste Charter proposes fundamental rights for children who are approaching the end of their lives. The charter will have achieved its purpose when every person caring for a dying child is capable of staying near the child until the last moments of his or her life, prepared to accept his or her death, ensuring both respect and dignity.


OBJECTIVE: In English paediatric practice, English law requires that parents and clinicians agree the 'best interests' of children and, if this is not possible, that the courts decide. Court intervention is rare and the concept of best interests is ambiguous. We report qualitative research exploring how the best interests standard operates in practice, particularly with decisions related to planned non-treatment. We discuss results in the light of accounts of best interests in the medical ethics literature. DESIGN: We conducted 39 qualitative interviews, exploring decision making in the paediatric intensive care unit, with doctors, nurses, clinical ethics committee members and parents whose children had a range of health outcomes. Interviews were audio-recorded and analysed thematically. RESULTS: Parents and clinicians indicated differences in their approaches to deciding the child's best interests. These were reconciled when parents responded positively to clinicians' efforts to help parents agree with the clinicians' view of the child's best interests. Notably, protracted disagreements about a child's best interests in non-
treatment decisions were resolved when parents' views were affected by witnessing their child's physical deterioration. Negotiation was the norm and clinicians believed avoiding the courts was desirable.

CONCLUSIONS: Sensitivity to the long-term interests of parents of children with life-limiting conditions is defensible but must be exercised proportionately. Current approaches emphasise negotiation but offer few alternatives when decisions are at an impasse. In such situations, the instrumental role played by a child's deterioration and avoidance of the courts risks giving insufficient weight to the child's interests. New approaches to decision making are needed.


Extracorporeal membrane oxygenation (ECMO) is a complex, highly technical surgical procedure that can offer hope for children born with congenital heart defects. The procedure may only briefly prolong a life, has limited potential for decreasing mortality, and may lead to serious complications, however. Perioperative nurses play an important role in caring for the child who requires ECMO. They are involved in assessing the child, implementing the plan of care, and facilitating communication between the child's family members and the health care team. Thus, perioperative nurses have a responsibility to consider the broad range of ethical issues associated with the procedure. By examining the ethical concepts of beneficence, nonmaleficence, autonomy, justice, and moral distress, the perioperative nurse can better understand the dilemmas that can affect the care and outcome of the critically ill child who requires ECMO.


Euthanasia was first legalised in the Netherlands in 2002, followed by similar legislation in Belgium the same year. Since the beginning, however, only the Netherlands included the possibility for minors older than 12 years to request euthanasia. In 2014, the Belgian Act legalising euthanasia was amended to include requests by minors who possess the capacity of discernment. This amendment sparked great debate, and raised difficult ethical questions about when and how a minor can be deemed competent. We conducted a systematic review of argument-based literature on euthanasia in minors. The search process followed PRISMA guidelines. Thirteen publications were included. The four-principle approach of medical ethics was used to organise the ethical arguments underlying this debate. The justification for allowing euthanasia in minors is buttressed mostly by the principles of beneficence and respect for autonomy. Somewhat paradoxically, both principles are also used in the literature to argue against the extension of legislation to minors. Opponents of euthanasia generally rely on the principle of nonmaleficence. CONCLUSION: The present analysis reveals that the debate surrounding euthanasia in minors is at an early stage. In order to allow a more in-depth ethical discussion, we suggest enriching the four-principle approach by including a care-ethics approach. What is Known: * The Netherlands and Belgium are the only two countries in the world with euthanasia legislation making it possible for minors to receive euthanasia. * This legislation provoked great debate globally, with ethical arguments for and against this legislation. What is New: * A systematic description of the ethical concepts and arguments grounding the debate on euthanasia in minors, as reported in the argument-based ethics literature. * A need has been identified to enrich the debate with a care-ethics approach to avoid oversimplifying the ethical decision-making process.

https://www.ncbi.nlm.nih.gov/pubmed/28573404

OBJECTIVE: Palliative sedation is a method of symptom management frequently used in hospices to treat uncontrolled symptoms at the end of life. There is a substantial body of literature on this subject; however, there has been little research into the experiences of hospice nurses when administering palliative sedation in an attempt to manage the terminal restlessness experienced by cancer patients.

METHOD: Semistructured interviews were conducted with a purposive sample of seven hospice nurses who had cared for at least one patient who had undergone palliative sedation within the past year in a hospice in the south of England in the United Kingdom. A phenomenological approach and Colaizzi’s stages of analysis were employed to develop themes from the data. RESULTS: Facilitating a “peaceful death” was the primary goal of the nurses, where through the administration of palliative sedation they sought to enable and support patients to be “comfortable,” “relaxed,” and “calm” at the terminal stage of their illness. Ethical dilemmas related to decision making were a factor in achieving this. These were: medication decisions, “juggling the drugs,” “causing the death,” sedating young people, the family “requesting” sedation, and believing that hospice is a place where death is hastened. SIGNIFICANCE OF RESULTS: Hospice nurses in the U.K. frequently encounter ethical and emotional dilemmas when administering palliative sedation. Making such decisions about using palliative sedation causes general discomfort for them. Undertaking this aspect of care requires confidence and competence on the part of nurses, and working within a supportive hospice team is of fundamental importance in supporting this practice.


https://www.ncbi.nlm.nih.gov/pubmed/27597732


Withdrawning Artificial Nutrition and Hydration (WANH) in the neonatal intensive care units (NICUs) has long been controversial. In France, the practice has become a legal option since 2005. But even though, the question remains as to what the stakeholders’ experience is, and whether they consider it ethically appropriate. In order to contribute to the debate, we initiated a study in 2009 to evaluate parental and health care professionals (HCP) perspectives, after they experienced WANH for a newborn. The study included 25 cases from 5 different clinical neonatology departments. We interviewed both the parents and some of the HCP who cared for the baby, at least 6 months after this latter deceased. We proceeded through in-depth individual qualitative interviews. Content was analyzed for themes and patterns that emerged from the data. Some parents expressed that WANH offered an opportunity to the family to spend a few demedicalized days with the baby before she dies, without any tubes and machines, and to be well supported by the HCP during this palliative stage. But others evaluated the practice in retrospect as a terrible ordeal. All said that, at least, the time of waiting for death to ensue should not last too long. After a few days, it becomes unbearable because of the transformation of the baby’s appearance and because they, as parents, began to wonder if she was not dying from starvation rather than from her initial disease. An important proportion of HCP also expressed some kind of ethical unease. This was due to the psychological violence involved in the decision for a human being to stop feeding a little one, and also to the difficulty to deal with the fundamental intention behind the decision of WANH: indeed, could it be claim that it does not presuppose the intention of provoking the infant’s death? The discussion focuses on the point to know if WANH can be considered as a source of progress from an ethical point of view, particularly in comparison with earlier practices—that in France could involve active euthanasia by lethal injection. We argue that when HCP are merely focused on avoiding that WAHN could be construed as a way of intending to hasten the baby’s death, the practice is at risk to be implemented in a way that becomes ethically counterproductive. Focusing on this intention easily distract the clinical teams from what should be their ultimate concern, namely the baby’s comfort during the dying process, as well as the support owned to her parents. To conclude, we suggest that the ethical priorities, when WANH is decided, should be the support due to the patient and
her family on the one hand, and, on the other hand to implement it in such a way that at least the baby seems to have died of her initial disease and never of starvation. This means that HCP have a duty to control the timing of death, even though this might be incompatible with the worry to avoid the intention of hastening the baby’s death.


Advances in perinatal science over the past five decades have reduced the practical ‘threshold of viability’ by approximately one week every 10 years such that survivors are expected as early as 22 weeks. Ethical standards regarding treatment of this periviable patient population remain enigmatic.

CONCLUSION: We review limitations in the current ethical rationale for caring for these infants in the delivery room and introduce an alternative utilising a delivery room hospice care approach involving the administration of opioids.


BACKGROUND: Professional organizations and governments recommend child and adolescent involvement in cancer treatment decision making (TDM) despite minimal evidence that children prefer involvement, how best to include them, and the result of doing so. PROCEDURE: Using descriptive qualitative research methods, we interviewed 20 children ages 9-17 years about their TDM preferences and experiences. We shifted our conceptualizations as findings emerged about how children with cancer viewed their decisional experiences. Results from constant comparative analysis of participant interviews yielded a new construct, "Having a say, as I need at this time" ("Having a Say"), which focuses more broadly on child communication preferences and the dynamism of those preferences. Ten additional interviews confirmed ‘Having a Say’ results. RESULTS: Children’s contextually related ‘Having a Say’ preferences ranged from not wanting to hear information at this time, to being included in treatment discussions, to choosing a treatment option. Children reported both positive and negative effects of being involved (or not) in treatment discussions as they preferred. Children’s preferences assumed the presence and involvement of their parents and doctors. Illness conditions (e.g., stage of treatment; symptom distress) informed child communication preferences more so than the child’s age.

CONCLUSIONS: The ‘Having a Say’ construct challenges the dominant shared TDM paradigm, which presumes it is best to involve children in their treatment decisions. ‘Having a Say’ is both a developmental and conceptual fit for children that can inform future research to develop and test clinical care approaches to meet child and adolescent communication needs.

We present a case of a fetal diagnosis of tricuspid atresia (TA). The pregnant woman and her husband requested that the baby be treated with only palliative care. The cardiologist did not think it would be appropriate to withhold life-prolonging surgery once the infant was born. The neonatologist argued that outcomes for TA are similar to those for hypoplastic left heart syndrome, and the standard practice at the institution was to allow parents to choose surgery or end-of-life care for those infants. The team requested an ethics consultation to assist in determining whether forgoing life-prolonging interventions in this case would be ethically supportable. In this article, we ask a pediatric intensivist, a pediatric cardiologist, and a neonatologist to discuss the ethics of withholding life-sustaining treatment of a baby with TA.


BACKGROUND: Some pregnant patients with complex fetal anomalies meet with paediatric palliative care subspecialists prior to delivery, but referral to antenatal palliative care consultation (APCC) is not standard. Little is known about its role in perinatal decision-making. METHODS: A single-centre retrospective cohort study was undertaken for patients referred for outpatient antenatal counselling by a neonatologist over a two-and-half-year period. Patients also receiving APCC were compared with infants with similar prognoses who did not. Outcomes assessed included antenatal decision-making, obstetric and neonatal outcomes. RESULTS: 24 (17%) of the 144 referred fetuses received APCC; nearly all had been given the prognoses of ‘non-survivable’ or ‘uncertain, likely poor’. Fetal or neonatal outcome included: fetal demise 5 (21%), in-hospital death 16 (67%) and survival to discharge (DC) 3(12%). 24 fetuses with similarly poor prognoses were not referred, but had similar outcomes: fetal demise 5 (21%), in-hospital death 16 (67%) and survival to DC 3 (12%). Those with APCC were more likely to choose comfort care than those without (67% vs 17%, p<0.01) and those who died in hospital had a shorter time to death than those who did not receive APCC. Less racial diversity was noted in the group receiving APCC. Infants with identified/suspected genetic syndromes were more likely to receive consultation despite similar mortality to the remaining cohort. CONCLUSIONS: Long-term outcomes with and without APCC were similar for infants with poor prognoses, though non-survivors with APCC were more likely to have a comfort care plan and shorter time to in-hospital death.


INTRODUCTION: The parents of children with severe spinal muscular atrophy (SMA) face difficult ethical decisions regarding their child’s treatment. This study explored the experience of parents of children with severe SMA concerning information and treatment decisions. MATERIAL AND METHODS: This nationwide survey, conducted in 2013, is based on parents of children who were born in Sweden between 2000 and 2010 and later diagnosed with SMA type I or II where respiratory support was considered the first year of life (N = 61, participation rate: 87%). The survey involved parents’ perception of the child’s care and the questions used in this study covered information given and treatment decisions. Descriptive statistics were used. RESULTS: None of the parents reported that the health care professionals made decisions concerning the child's treatment without informing them first, and 80% reported feeling confident about the decisions made. Of the bereaved parents, 11/48 (23%) reported that they got no information about respiratory support, compared to 2/13 (15%) of non-bereaved. Bereaved parents were more likely to report being satisfied with and understanding the information given about the illness and its treatment than non-bereaved parents. CONCLUSION: All parents reported having been informed before treatment decisions were made and a vast majority reported feeling confident about the decisions. However, a quarter of the parents declined to have received information...
about respiratory support, which indicates that the parents did not sufficiently understand the available respiratory treatment options, and that their children may not receive the kind of care that is recommended in guidelines.


Clinicians may face new ethical considerations when parents continue pregnancies after receiving life-limiting fetal diagnoses and desire palliative care. In this article we present four ethical considerations in perinatal palliative care: ambiguous terminology in relation to diagnosis or prognosis, differences between bereavement support and palliative care, neonatal organ donation, and postdeath cooling. In this article, we enable readers to consider current topics from different perspectives and reflect on care when confronted with sensitive clinical scenarios.


Many babies with trisomy 13 and 18 die in the first year of life. Survivors all have severe cognitive impairment. There has been a debate among both professionals and parents about whether it is appropriate to provide life-sustaining interventions to babies with these serious conditions. On one side of the debate are those who argue that there is no point in providing invasive, painful, and expensive procedures when the only outcomes are either early death or survival with severe cognitive impairment. Others suggest that, although mortality is high and cognitive impairment universal, babies with these conditions have an acceptable quality of life. In this paper, we will discuss both points of view. We will review the ways in which these conditions are portrayed in pediatrics textbooks and on social media sites that offer support to parents. We will then suggest an appropriate way to deal with clinical decisions for babies with these trisomies.


PURPOSE: The so-called lethal malformations pose ethical challenges. Most affected fetuses die before or at birth. Live-born neonates commonly receive palliative care. If the postnatal course is better than expected, redirection towards more treatment may occur. We aimed to analyze this in a Swiss patient cohort. MATERIALS AND METHODS: Over 6 years, fetal malformation was suspected in 1113 cases. We identified patients prenatally assigned to palliative care, assessed pre- and postnatal diagnoses, and outcomes. RESULTS: Fourteen neonates received palliative care. Eleven patients received palliative care following late termination of pregnancy, for three, palliative care was planned and the fetus died during delivery, for two, the outcome was unknown (incomplete documentation). Genetic testing was performed in 50%. The predominant diagnostic group was central nervous system malformations (33%), followed by chromosomal aberrations (20%) and renal anomalies (17%). One child assigned to palliative care was resuscitated. Antenatal findings were anhydramnios and pulmonary hypoplasia. Postnatally, respiration was better than expected. The neonate was admitted to intensive care, died on day one.

CONCLUSIONS: Nervous system malformations seem to be a major criterion for foregoing life-sustaining interventions. Direction towards more treatment is rare. This may reflect precise prenatal prognostication; a degree of self-fulfilling prophecy cannot be excluded.


BACKGROUND: In the last decade, the number of children with life-limiting and life-threatening conditions in England has almost doubled, and it is estimated that worldwide, there are 1.2 million children with palliative care needs. Families and professionals caring for children with life-limiting conditions are likely to face a number of difficult treatment decisions and develop plans for future care over the course of the child’s life, but little is known about the process by which these decisions and plans are made. METHODS: The purpose of this review is to synthesize findings from qualitative research that has investigated decision-making and future planning for children with life-limiting conditions. A systematic search of six online databases was conducted and identified 887 papers for review; five papers were selected for inclusion, using predefined criteria. Reference list searching and contacting authors identified a further four papers for inclusion. RESULTS: Results sections of the papers were coded and synthesized into themes. Nineteen descriptive themes were identified, and these were further synthesized into four analytical themes. Analytical themes were ‘decision factors’, ‘family factors’, ‘relational factors’ and ‘system factors’. CONCLUSIONS: Review findings indicate that decision-making and future planning is difficult and needs to be individualized for each family. However, deficits in understanding the dynamic, relational and contextual aspects of decision-making remain and require further research.


Importance: For clinicians caring for adolescent patients living with progressive, life-threatening illness, discussions regarding prognosis, goals of care, and treatment options can be extremely challenging. While clinicians should respect and help to facilitate adolescents’ emerging autonomy, they often must also work with parents’ wishes to protect patients from the emotional distress of hearing bad news. Observations: We reviewed the ethical justifications for and against truth-telling, and we considered the published ethical and practice guidance, as well as the perspectives of patients, parents, and clinicians involved in these cases. We also explored particular challenges with respect to the cultural context, timing, and content of conversations at the end of adolescents' lives. In most cases, clinicians should gently but persistently engage adolescents directly in conversations about their disease prognosis and corresponding hopes, worries, and goals. These conversations need to occur multiple times, allowing significant time in each discussion for exploration of patient and family values. While truth-telling does not cause the types of harm that parents and clinicians may fear, discussing this kind of difficult news is almost always emotionally distressing. We suggest some "phrases that help" when clinicians strive to deepen understanding and facilitate difficult conversations with adolescents, parents, and other family members. Conclusions and Relevance: The pediatrician’s opportunities to engage in difficult conversations about poor prognosis may be rare, but such conversations can be crucial. These discussions affect how patients live at the end of their lives, how they die, and how their families go on. Improved understanding of basic principles of communication, as well as augmented understanding of patient, family, and clinician perspectives may better enable us to navigate these important conversations.


After reviewing the existing bibliography in the last 20 years, we concluded that there is a lack of information regarding the ethical conflicts that affect to pediatrics in their daily practice. It produces certain degree of uncertainty in these professionals at the time of solving these problems. We made a systematic search in the main data bases, finding more than 150 articles related, of which 80 were considered outstanding. After studying them, we have found 40 ethical dilemmas, related to some principle of solution and that we described in this article. Through them we can find such important dilemmas as those related to physical disability, palliative care or consent from children.

BACKGROUND: Medical trainees consistently report suboptimal instruction and poor self-confidence in communication skills. Despite this deficit, few established training programs provide comprehensive, pediatric-specific communication education, particularly in the provision of "bad news." To our knowledge, no programs currently use bereaved parent educators to facilitate communication training for pediatric subspecialty trainees. PROCEDURE: The authors designed and implemented a pilot communication training seminar in which bereaved parent educators and faculty facilitators led small groups in interactive, role-play scenarios. Surveys incorporating a retrospective preprogram assessment item to account for response-shift bias were used to assess short- and long-term changes in trainee comfort with delivering "bad news." RESULTS: Fifteen pediatric fellowship trainees participated in the communication seminar; complete data were available for 12 participants. After accounting for response-shift bias, participants reported significant improvement in overall preparedness, breaking bad news to a patient and family, and including the adolescent or young adult patient in conversations. Additionally, participants reported a significant improvement in their ability to address a patient and family’s need for information, emotional suffering at the end of life (EOL), if and when a patient should be included in the conversation, and EOL care decisions. The participant’s self-perceived improvement in comfort and preparedness persisted over time. CONCLUSIONS: Communication training for pediatric subspecialty trainees using bereaved parent educators is feasible and effective. Both medical trainee and bereaved parent participants benefited from involvement in this pilot study. Further iterations of this training will be modified to assess objective measures of improvement in trainees’ communication skills.


AIM: To discuss corporeal support of the brain-dead pregnant woman and to critically examine important aspects of this complex situation that remain as yet unexplored. BACKGROUND: When brain death of the woman occurs during pregnancy, the fetus may be kept inside the corporeally supported body for prolonged periods to enable continued fetal growth and development. This has been increasingly reported in medical literature since 1982 and has received considerable media attention in the past few years. IMPLICATIONS FOR MIDWIVES AND NURSES: Sophisticated advances in medical technologies have altered the boundaries of conception and birth, life and death, Western biomedical and cultural conceptions of women and their bodies, fetal personhood, fetal rights and fetal patienthood, profoundly influencing maternal behaviors, medical decisions and the treatment of pregnant women. This is especially so in the rare, but fraught instance of brain death of the pregnant woman, where nurses and midwives working in High Dependency Care units undertake the daily care of the corporeally supported body that holds a living fetus within it. This discussion enables critical and ethical conversation around the complexities of developing appropriate discourse concerning the woman who suffers brain death during pregnancy and considers the complexities for nurses and midwives caring for the Woman/body/fetus in this context. The potential impact on the fetus of growing and developing inside a 'dead' body is examined, and the absence in the literature of long-term follow up of infants gestated thus is questioned.


Resuscitation decisions for infants born at the edges of viability are complicated moral dilemmas, and the process of making these decisions is emotionally exhausting and morally distressful for families and physicians alike. An ethical approach to making these decisions requires input from physicians and
parents; individuals tasked with facilitating such decisions must possess the communication and counseling skills needed to assist families with these painful and life-altering decisions. It is incumbent on all of us to continue our investigation into how we can better assist families in this process while providing care that is in their best interest.


Tate, T., A. Goldberg, A. Wightman, B. A. Warady and J. D. Lantos (2017). "Controversy About Dialysis for an Adolescent." *Pediatrics* 140(1).

For patients on dialysis, 1 frequent cause of death is their voluntary decision to discontinue dialysis. Such decisions raise complex questions when the patient is a competent adult. The decisions are even more complex when the patient is an adolescent. In this article, we present a case in which a 17-year-old adolescent decided that she no longer wished to undergo dialysis through her fistula. Her doctors thought that dialysis using any other technique would be too dangerous. Four experts in pediatric nephrology, bioethics, and palliative care discuss this decision and the different ways that the health care team might respond.


OBJECTIVE: Some of the antenatally diagnosed fetal pathologies are unlikely to get compatible with life. Still some women choose to continue with pregnancy. Subsequently, perinatal palliative care (PPC) has become a constructive demarche in such situations. Our study, based on a multicentric survey, reports some cases of fetal pathologies considered as lethal according to perinatal professionals and reveals the decisional process in each case. METHODS: We sent by emails a questionnaire to 434 maternal-fetal medicine specialists and fetal care pediatric specialists at 48 multidisciplinary centers for prenatal diagnosis. RESULTS: The participation rate was 49.3%. In total, 61 obstetric-gynecologists and 68 neonatologists completed the survey. The results showed that 35.4% of the pregnant women asked for the continuation of pregnancy and 24.7% asked for the termination of pregnancy. More than half of professionals (52.9%) took the initiative of informing women about the options for birth support (including PPC), while 32.7% of obstetric gynecologists did not take this initiative versus 10.2% of neonatologists (p < 0.01). CONCLUSION: This study demonstrates the absolute need to provide PPC training for professionals and to standardize its practices.


Pediatric palliative care providers often care for children with rare, poorly understood diseases. In addition to grappling with a life-limiting diagnosis, families face complexity in decision making stemming from the prognostic uncertainty surrounding their child’s rare condition. We discuss several unique challenges, illustrated through case studies of three children who shared the rare diagnosis of congenital disorder of glycosylation.


Many families of patients hold the view that it is their right to be present during a loved one’s resuscitation, while the majority of patients also express the comfort and support they would feel by having them there. Currently, family presence is more commonly accepted in paediatric cardiopulmonary
resuscitation (CPR) than adult CPR. Even though many guidelines are in favour of this practice and recognise potential benefits, healthcare professionals are hesitant to support adult family presence to the extent that paediatric family presence is supported. However, in this paper, we suggest that the ethical case to justify family presence during paediatric resuscitation (P-FPDR) is weaker than the justification of family presence during adult resuscitation (A-FPDR). We go on to support this claim using three main arguments that people use in clinical ethics to justify FPDR. These include scarcity of evidence documenting disruption, psychological benefits to family members following the incident and respect for patient autonomy. We demonstrate that these arguments actually apply more strongly to A-FPDR compared with P-FPDR, thereby questioning the common attitude of healthcare professionals of allowing the latter while mostly opposing A-FPDR. Importantly, we do not wish to suggest that P-FPDR should not be allowed. Rather, we suggest that since P-FPDR is commonly (and should be) allowed, so should A-FPDR. This is because the aforementioned arguments that are used to justify FPDR in general actually make a stronger case for A-FPDR.


Ethical issues in the field of pediatric neurosurgery, including prenatal diagnosis, palliative care for children with an intractable serious disease, and medical neglect, are discussed. An important role of medicine is to offer every possible treatment to a patient. However, it also is the responsibility of medicine to be conscious of its limitations, and to help parents love and respect a child who suffers from an incurable disease. When dealing with cases of medical neglect and palliative care for an incurable disease, it is critical to diagnose the child’s condition accurately and evaluate the outcome. However, to treat or not to treat also depends on the medical resources and social-economic status of the community, the parents’ religion and philosophy, the policies of the institutions involved, and the limits of medical science. Moral dilemmas will continue to be addressed as medical progress yields treatments for untreatable diseases in the future.

One in four people show a ‘worrying’ lack of understanding about children's hospices and palliative care, a survey shows.


BACKGROUND: ECCO essential requirements for quality cancer care (ERQCC) are checklists and explanations of organisation and actions that are necessary to give high-quality care to patients who have a specific tumour type. They are written by European experts representing all disciplines involved in cancer care. ERQCC papers give oncology teams, patients, policymakers and managers an overview of the elements needed in any healthcare system to provide high quality of care throughout the patient journey. References are made to clinical guidelines and other resources where appropriate, and the focus is on care in Europe. Sarcoma: essential requirements for quality care * Sarcomas - which can be classified into soft tissue and bone sarcomas - are rare, but all rare cancers make up more than 20% of cancers in Europe, and there are substantial inequalities in access to high-quality care. Sarcomas, of which there are many subtypes, comprise a particularly complex and demanding challenge for healthcare systems and providers. This paper presents essential requirements for quality cancer care of soft tissue sarcomas in adults and bone sarcomas. * High-quality care must only be carried out in specialised sarcoma centres (including paediatric cancer centres) which have both a core multidisciplinary team and an extended team of allied professionals, and which are subject to quality and audit procedures. Access to such units is far from universal in all European countries. * It is essential that, to meet European aspirations for high-quality comprehensive cancer control, healthcare organisations implement the requirements in this paper, paying particular attention to multidisciplinarity and patient-centred pathways from diagnosis and follow-up, to treatment, to improve survival and quality of life for patients. CONCLUSION: Taken together, the information presented in this paper provides a comprehensive description of the essential requirements for establishing a high-quality service for soft tissue sarcomas in adults and bone sarcomas. The ECCO expert group is aware that it is not possible to propose a ‘one size fits all’ system for all countries, but urges that access to multidisciplinary teams is guaranteed to all patients with sarcoma.


OBJECTIVE: Neonatal nurses face numerous barriers in providing end-of-life (EOL) care for neonates and their families. Addressing neonatal nurses' attitudes could provide insight into barriers that impede
neonatal palliative care (NPC). This study thus conducted to examine neonatal nurses’ attitude toward barriers in providing NPC in Southeast Iran. METHOD: In this cross-sectional study, a translated modified version of Neonatal Palliative Care Attitude Scale was used to examine attitudes of 70 nurses toward barriers of palliative care in 3 neonatal intensive care units in Southeast Iran. RESULTS: Findings indicated that overall 42.63% of nurses were strongly agreed or agreed with the proposed barriers in NPC. Among all categories, the highest and the lowest scores belonged to the categories of "insufficient resources" (3.42 +/- 0.65) and "inappropriate personal and social attitudes" (2.33 +/- 0.48), respectively. Neonatal nurses who had less education and study regarding NPC reported the presence of more barriers to NPC in the categories of "inappropriate organizational culture" and/or "inadequate nursing proficiency." Also, younger nurses had more positive attitudes toward the category of inappropriate organizational culture as being a barrier to provision of NPC (4.62). CONCLUSION: The findings suggest that developing a context-based instrument is required to represent the barrier more precisely. Neonatal palliative care can be improved by establishing a special environment to focus on infants’ EOL care. This establishment requires standard palliative care guidelines and adequate NPC-trained nurses.


PURPOSE: We aimed to assess the viewpoints, experiences, and preferences within the clinical communication triangle (parent, adolescent, health care team) concerning the information-sharing process for adolescents with cancer. METHODS: This is a qualitative descriptive-exploratory study. Overall, 33 participants were recruited (adolescents diagnosed with cancer aged 15-20 years, their parents, oncologists, and nurses). In-depth semi-structured interviews were conducted and data were analyzed using constant comparative analysis. RESULTS: Data analysis yielded three main themes. Disaffiliation of adolescents in information-sharing process with three subthemes: confusion and unanswered questions; and, seeking information from inferior sources. Barriers to information-sharing with three subthemes: parents as gatekeepers in the information-sharing process, cultural background creating strong barriers for information-sharing, and the negative attitude of the medical team towards information-sharing. The last theme is cornerstones in information-sharing process with three subthemes: trust and honesty to enhance communication between adolescents and the medical team, the necessity of paving the way for information-sharing, and the value of gradual information-sharing based on the adolescents need and mental readiness. CONCLUSION: Participants believed that information-sharing was insufficient and provided recommendations for facilitating this process. Information-sharing process needs to be gradual and based on the adolescent’s need and mental capacity. Future research needs to focus on devising a protocol for information-sharing with adolescents with cancer that accounts for familial and cultural factors, is carefully timed, and provides clearer and more efficacious communication between parents, adolescents, and the health care team.


While availability of palliative care consultation for children with advanced heart disease increases, little is known about cardiologist attitudes towards palliative care. We sought to describe perspectives of cardiologists regarding palliative care and to characterize their perceived competence in palliative care concepts. A cross-sectional survey of pediatric cardiologists and cardiac surgeons from 19 pediatric medical centers was performed. Overall response rate was 31% (183/589). Respondents had a median of 18 years of experience since medical school (range 2-49) and most practiced at academic centers (91%). Sixty-percent of respondents felt that palliative care consultations occur "too late" and the majority (85%) agreed that palliative care consultations are helpful. Barriers to requesting palliative care consultation were most frequently described as "referring to palliative care services too early will
undermine parents' hope" (45%) and "concern that parents will think I am giving up on their child" (56%). Only 33% of cardiologists reported feeling "very" or "moderately" competent in prognosticating life expectancy while over 60% felt competent caring for children with heart disease around end of life, and nearly 80% felt competent discussing goals of care and code status. Greater perceived competence was associated with subspecialty (heart failure/intensivist vs. other) (OR 3.6, 95% CI 1.6-8.1, p = 0.003) and didactic training (OR 6.27, 95% CI 1.8-21.8, p = 0.004). These results underscore the need for further training in palliative care skills for pediatric cardiologists. Enhancing palliative care skills among cardiologists and facilitating partnership with subspecialty palliative care teams may improve overall care of children with advanced heart disease.


BACKGROUND: Studies have shown that pediatricians in all stages of training are uncomfortable managing patients at end of life. Our goal was to create and test a portable reference card to improve pediatric resident education in comprehensive care for children nearing end of life. METHODS: We evaluated the impact of the Pediatric End-of-Life Care Management Reference Card on residents' perceived comfort and knowledge through pre- and post-intervention surveys. The preintervention questionnaires and pocket cards were distributed to all first- and second-year residents, and then a follow-up survey was provided six months later. Based on Likert scales, questions focused on self-reported understanding of palliative care principles and knowledge regarding and comfort in performing end-of-life symptom management. RESULTS: Twenty-six pediatric residents completed pre- and post-intervention surveys. Following receipt of the reference card, no significant changes were noted consistently across all groups of residents. The majority of improvements were noted when comparing second to third year residents, including knowledge and comfort related to pain management, comfort in managing secretions and nausea, and documentation following death. The first to second year residents demonstrated improvement in knowing what language to use to tell a family that their child has died. CONCLUSION: This study demonstrates that a portable reference card may be a convenient, simple, and useful component of education for pediatric residents in end-of-life care management. This reference card is a foundation from which to develop a standardized educational tool. Additional research is required to assess the impact of this type of intervention in pediatric palliative care education.


BACKGROUND: Prior research has shown that less than 40% of pediatric program directors believe their graduating residents competent in palliative care. While many curricula have been developed to address this need, few have demonstrated improved comfort and/or knowledge with palliative care principles. The purpose of this study was to test a pocket card educational intervention regarding resident knowledge and comfort with palliative care principles. METHODS: Pocket reference cards were created to deliver fundamentals of pediatric palliative care to resident learners; didactics and case studies emphasized principles on the cards. Self-reported comfort and objective knowledge were measured before and after the curriculum among residents. RESULTS: Of 32 post-graduate year 2 (PGY2) residents, 23 (72%) completed the pre-test survey. The post-test was completed by 14 PGY2 residents (44%) and 16 of 39 PGY3/4 residents (41%). There was improvement in comfort with communication, as well as pain and symptom management among the residents. Knowledge of palliative care principles improved in part, with only a few survey questions reaching statistical significance. 100% of respondents recommended the cards be provided to their colleagues. CONCLUSION: This longitudinal curriculum, designed specifically for pediatric residents, was built into an existing training program and proved to be popular, feasible, and effective at improving comfort with basic palliative care principles.

OBJECTIVE: The objective of this exploratory study is to describe communication between physicians and the actor parent of a standardized 8-year-old patient in respiratory distress who was nearing the end of life. METHODS: Thirteen pediatric emergency medicine and pediatric critical care fellows and attendings participated in a high-fidelity simulation to assess physician communication with an actor-parent. RESULTS: Fifteen percent of the participants decided not to initiate life-sustaining technology (intubation), and 23% of participants offered alternatives to life-sustaining care, such as comfort measures. Although 92% of the participants initiated an end-of-life conversation, the quality of that discussion varied widely. CONCLUSION: Findings indicate that effective physician-parent communication may not consistently occur in cases involving the treatment of pediatric patients at the end of life in emergency and critical care units. PRACTICE IMPLICATIONS: The findings in this study, particularly that physician-parent end-of-life communication is often unclear and that alternatives to life-sustaining technology are often not offered, suggest that physicians need more training in both communication and end-of-life care.


BACKGROUND: There is a paucity of data in the literature regarding end-of-life care and do-not-resuscitate (DNR) status of the pediatric surgical patient, although invasive procedures are frequently performed in very high risk and critically ill children. Despite significant efforts in adult medicine to enhance discussions around end-of-life care, little is known about similar endeavors in the pediatric population. METHODS: A retrospective review of the National Surgical Quality Improvement Program Pediatric database was performed. Patients aged <18 y with American Society of Anesthesiologists class 3 or greater who underwent elective surgical procedure in 2012-2013 were included. Demographic factors, principal diagnosis, associated conditions, DNR status, and mortality were extracted. Descriptive analysis was performed. RESULTS: A total of 20,164 patients met the inclusion criteria. Only 36 (0.2%) patients had a signed DNR order before surgical procedure. Of severely ill American Society of Anesthesiologists four patients, only 1% had DNR status. There were no differences in gender, race, ethnicity, or surgical specialty by the presence of a DNR order. Notably, 17.1% of children who died within this period had multiple surgical procedures performed before expiring. CONCLUSIONS: The rate of documented DNR status is extremely low in the high-risk pediatric surgical population undergoing elective surgery, even among severely ill children. Well-informed end-of-life care discussions in a patient-focused approach are essential in the surgical care of children with complex medical conditions and critical illness. Better documentation of DNR discussion will also allow better tracking and benchmarking.


OBJECTIVE: Compassion fatigue, burnout, and vicarious traumatization are prominent topics in the current literature on the impact of the rewarding but challenging work of healthcare professionals who care for patients with life-limiting illnesses. The positive effects of caregiving constitute a newly emerging outcome that has been relatively unexplored in the pediatric literature, and yet they may play an important role in contributing to the satisfaction and well-being of the healthcare professionals who care for children who have a life-limiting illness. METHOD: This paper reports the results of a secondary analysis of qualitative interview transcripts that explored the experiences of hospital-based pediatric
healthcare providers caring for children with varied life-limiting illnesses. In-depth qualitative interviews were conducted with 25 healthcare professionals (9 social workers, 8 nurses, and 8 physicians). The majority of participants were women (80%), with an age range between 20 and 60 years, and most (84%) had the experience of caring for more than 15 dying children. Thematic analysis was conducted using interpretive description and constant comparison. RESULTS: Every healthcare professional interviewed experienced personal growth as a result of their providing care for dying children. Three dimensions of personal growth were most consistently reported: (1) new or altered life perspectives, (2) enhanced personal resources, and (3) benevolence. SIGNIFICANCE OF RESULTS: A deeper understanding of the phenomenon of personal growth could help healthcare organizations to implement innovative approaches that would counterbalance compassion fatigue, and thereby enhance both healthcare provider well-being and child and family outcomes.


A survey of 146 pediatric care providers (PCPs) revealed that 75.3% were unaware that children with epilepsy were at risk of death, specifically from sudden unexpected (or unexplained) death in epilepsy (SUDEP). PCPs assume that the treating neurologist discusses these risks. Increasing PCPs’ knowledge of SUDEP will help address the care gap related to informing families about SUDEP.


The relationship between parents and clinician is critical to the care and treatment of children with life-limiting conditions (LLCs) and life-threatening illnesses (LTIs). This relationship is built and maintained largely in consultations. In this article we lay out factors that bear on the success of clinical consultations and the maintenance of the essential clinician-parent relationship at progression or deterioration of LLCs or LTIs. We suggest an approach to engaging parents in conversations about care and treatment that recognises and appreciates the dilemmas which clinicians and parents face and in so doing provides a way for everyone to live with the decisions that are made. A close analysis of a consultation at progression and excerpts of encounters among parents, clinician and researcher are used to illustrate our approach to research, analysis and development of recommendations for clinical practice.


AIM: Paediatricians caring for severely ill children may receive requests for physician-assisted dying (PAD). Dutch euthanasia law only applies to patients over 12 who make well-considered requests. These
limitations have been widely debated, but little is known about paediatricians’ positions on PAD. We explored the situations in which paediatricians found PAD conceivable and described the roles of the patient and parents, the patient’s age and their life expectancy. METHODS: We sent a questionnaire to a national sample of 276 Dutch paediatricians and carried out semi-structured interviews with eight paediatricians. RESULTS: The response rate was 62%. Most paediatricians said performing PAD on request was conceivable (81%), conceivability was independent of the patient’s age and whether the patient or parent(s) requested it. The paediatricians interviewed felt a duty to relieve suffering, irrespective of the patient’s age or competency to decide. When this was not possible through palliative care, PAD was seen as an option for all patients who were suffering unbearably, although some paediatricians saw parental agreement and reduced life expectancy as prerequisites. CONCLUSION: Most Dutch paediatricians felt PAD was conceivable, even under the age of 12 if requested by the parents. They seemed driven by a sense of duty to relieve suffering.


OBJECTIVE: In the paediatric intensive care unit (PICU), medication administration is challenging. Empirical studies demonstrate that interruptions occur frequently and that nurses are fundamental in the delivery of medication. However, little is known about nurse’s decision making when interrupted during medication administration. Therefore, the objective is to understand decision making when interrupted during medication administration within the PICU. RESEARCH DESIGN: A qualitative study incorporating non-participant observation and audio recorded semi-structured interviews. A convenience sample of ten PICU nurses were interviewed. Each interview schedule was informed by two hours of observation which involved a further 29 PICU nurses. Data was analysed using Framework Analysis. SETTING: A regional PICU located in a university teaching hospital in the United Kingdom. FINDINGS: Analysis resulted in four overarching themes: (1) Guiding the medication process, (2) Concentration, focus and awareness, (3) Influences on interruptions (4) Impact and recovery CONCLUSION: Medication administration within the PICU is an essential but complex activity. Interruptions can impact on focus and concentration which can contribute to patient harm. Decision making by PICU nurses is influenced by interruption awareness, fluctuating levels of concentration, and responding to critically ill patient and families’ needs.


Systems thinking is used as a way of understanding behaviours and actions in complex healthcare organisations. An important premise of the concept is that every action in a system causes a reaction elsewhere in that system. These reactions can lead to unintended consequences, sometimes long after the original action, and so are not always attributed to them. This article applies systems thinking to a medicines management case study, to highlight how quality-improvement practitioners can use the approach to underpin planning and implementation of patient-safety initiatives. The case study is specific to transcribing in children’s hospices, but the strategies can be applied to other areas. The article explains that, while root cause analysis tools are useful for identifying the cause of, and possible solutions to, problems, they need to be considered carefully in terms of unintended consequences, and how the system into which the solution is implemented can be affected by the change. Analysis of problems using a systems-thinking approach can help practitioners to develop robust and well informed business cases to present to decision makers.

BACKGROUND: Pediatric fellows receive little palliative care (PC) education and have few opportunities to practice communication skills. OBJECTIVE: In this pilot study, we assessed (1) the relative effectiveness of simulation-based versus didactic education, (2) communication skill retention, and (3) effect on PC consultation rates. DESIGN: Thirty-five pediatric fellows in cardiology, critical care, hematology/oncology, and neonatology at two institutions enrolled: 17 in the intervention (simulation-based) group (single institution) and 18 in the control (didactic education) group (second institution). Intervention group participants participated in a two-day program over three months (three simulations and videotaped PC panel). Control group participants received written education designed to be similar in content and time. MEASUREMENTS: (1) Self-assessment questionnaires were completed at baseline, post-intervention and three months; mean between-group differences for each outcome measure were assessed. (2) External reviewers rated simulation-group encounters on nine communication domains. Within-group changes over time were assessed. (3) The simulation-based site’s PC consultations were compared in the six months pre- and post-intervention. RESULTS: Compared to the control group, participants in the intervention group improved in self-efficacy (p = 0.003) and perceived adequacy of medical education (p < 0.001), but not knowledge (p = 0.20). Reviewers noted nonsustained improvement in four domains: relationship building (p = 0.01), opening discussion (p = 0.03), gathering information (p = 0.01), and communicating accurate information (p = 0.04). PC consultation rate increased 64%, an improvement when normalized to average daily census (p = 0.04). CONCLUSIONS: This simulation-based curriculum is an effective method for improving PC comfort, education, and consults. More frequent practice is likely needed to lead to sustained improvements in communication competence.


OBJECTIVE: Our aims were to report an analysis of the concept of cultural competency and to explore how the cultural competency of the palliative care workforce impacts the holistic care of young people with palliative care needs from South Asian cultures. METHOD: Using keywords, we searched the online databases MEDLINE, CINAHL, ScienceDirect, and PubMed from January of 1990 through to December of 2016. Some 1543 articles were retrieved, and inclusion and exclusion criteria were applied. A total of 38 papers were included in the concept analysis. The data were analyzed using Coad’s (2002) adapted framework based on Rodgers’s (1989) evolutionary concept analysis, focusing on the attributes, antecedents, consequences, and related terms in relation to culturally competent care. A model case of culturally competent care was also constructed. RESULTS: The literature provides evidence that the concept of culturally competent care is a complex one, which is often expressed ambiguously. In addition, there is a paucity of research that involves service users as experts in defining their own needs and assessing their experiences related to cultural care. SIGNIFICANCE OF RESULTS: Cultural care should be integral to holistic patient care, irrespective of a person’s race or ethnicity. There is an urgent need to involve young BAME patients with palliative care needs and their families in the development of a robust tool to assess cultural competency in clinical practice.


BACKGROUND: The question 'would you be surprised if this patient died in the next 12-months’ is widely used for identifying adult patients in the last year of life. However, this has not yet been studied in children. AIM: To assess the prognostic accuracy of the surprise question when used by a multidisciplinary team to predict survival outcomes of children with life-limiting conditions over a 3 and 12 month period. DESIGN: A prospective cohort study. SETTING/PARTICIPANTS: Six multidisciplinary team members working in a children's hospice answered a 3 and 12 month surprise question about 327 children who were either newly referred or receiving care at the hospice between 2011 and 2013.
RESULTS: The prognostic accuracy of the multidisciplinary team for the 3 (and 12) month surprise question were: sensitivity 83.3% (83.3%), specificity 93.2% (70.7%), positive predictive value 41.7% (23.6%), negative predictive value 99% (97.5%) and accuracy 92.6% (71.9%). Patients with a 'no' response had an increased risk of death at 3 (hazard ratio, 22.94, p 0.001) and 12 months (hazard ratio, 6.53, p 0.001). CONCLUSION: The surprise question is a highly sensitive prognostic tool for identifying children receiving palliative care who are in the last 3 and 12 months of life. The tool is accurate at recognising children during stable periods demonstrated through a high negative predictive value. In practice, this tool could help identify children who would benefit from specialist end of life care, act as a marker to facilitate communications on advance care planning and assist in resource allocation.


Recruitment of participants into bereavement research may present many challenges for the research team. At present, there is little consensus for researchers and ethics committees on the most appropriate method of recruitment. There is some evidence that participants prefer to be contacted about research studies via letters. However, recruitment involving the use of a letter can occur in a number of ways, each with ethical and practical benefits and limitations. In a study of the experiences of bereaved parents, we used letters in three ways: direct mailing from the research team with an opt-out option; permission to mail letters obtained by social workers from a hospital-based follow-up program during routine contact; and letters mailed from the hospital's PICU research nurse at the hospital with instruction on how to opt in. In this paper, the practical and ethical realities of each method are highlighted, using examples from our own experiences. Nineteen parents also provided reflections in follow-up phone calls. While direct researcher contact is perhaps the most feasible for researchers, ethical concerns may render it unacceptable. While contact via a known member of a follow-up program is more ethically appropriate for participants, it also presents significant practical issues. We suggest that contact via a representative of the healthcare institution provides the best balance of ethical and practical acceptability for both participants and the research team, but responsiveness to the ethical and practical requirements of the study is crucial in ensuring it can be successfully undertaken. (c) 2017 Wiley Periodicals, Inc.


BACKGROUND: Fetal malformations occur in 2% of gestations and are the fifth most common cause of neonatal death in the world. In many cases, fetal malformations result in neonatal death or long stay in intensive care facilities. Families that continue the pregnancy in such a situation need to make choices and cope with an overwhelming number of potential issues. Palliative care starting at the prenatal period is a growing field that allows the entire family to prepare for this difficult situation. OBJECTIVE: To perform a systematic review of published data on palliative care in the prenatal period. DESIGN: PubMed and the Cochrane Library were searched using the keywords ("perinatal" OR "prenatal" OR "fetal") AND "palliative care" and also ("perinatal" OR "prenatal" OR "fetal") AND "hospice." SETTING/SUBJECTS: Studies focusing on the long-term impact of prenatal palliative care published up to December 2015 were used. MEASUREMENTS: Quantitative and qualitative studies. RESULTS: In total, 541 studies were retrieved; 29 articles met the inclusion criteria. Studies were organized into different categories according to the design or main focus. The majority of studies retrieved were reflexives or presented a narrative proposal on palliative care started in the prenatal period (45%). Clinical studies comprised 17% of all articles found. No studies were found on the long-term impact of prenatal palliative care. CONCLUSIONS: Prenatal palliative care is a growing field and an important supportive care measure that can help grieving parents and families who do not want to or cannot interrupt their pregnancy. More studies should be carried out, specifically concerning long-term impact of prenatal palliative care.
Guidelines and training of health professionals must be developed so that more families can benefit from this type of care.


BACKGROUND: Family conferences in the pediatric intensive care unit (ICU) often include palliative care (PC) providers. We do not know how ICU communication differs when the PC team is present. AIM: To compare language used by PC team and ICU physicians during family conferences. DESIGN: A retrospective cohort review of ICU family conferences with and without the PC team. SETTING: Forty-four bed pediatric ICU in a tertiary medical centre. PARTICIPANTS: Nine ICU physicians and 4 PC providers who participated in 18 audio-recorded family conferences. RESULTS: Of the 9 transcripts without the PC team, we identified 526 ICU physician statements, generating 10 thematic categories. The most common themes were giving medical information and discussing medical options. Themes unique to ICU physicians included statements of hopelessness, insensitivity, and "health-care provider challenges." Among the 9 transcripts with the PC team, there were 280 statements, generating 10 thematic categories. Most commonly, the PC team offered statements of support, giving medical information, and quality of life. Both teams promoted family engagement by soliciting questions; however, the PC team was more likely to use open-ended questions, offer support, and discuss quality of life. CONCLUSION: Pediatric ICU physicians spend more time giving medical information, whereas the PC team more commonly offers emotional support. The addition of the PC team to ICU family conferences may provide a balanced approach to communication.


The charity Together for Short Lives has launched a campaign to encourage nurses to consider a role in children's palliative care in the voluntary sector, to prevent any further reduction in services for this already vulnerable group.


CONTEXT: Difficult family conversations are a challenge for even the most seasoned clinicians. Teaching the skills of successful communication between providers, family members, and patients is a vital component of medical education. However, traditional teaching methods using didactics and expert role modeling are often inadequate. OBJECTIVES: The train-the-educator workshop aimed to teach educators how to create and conduct workshops on facilitating difficult family conversations that target their own learners’ needs. METHODS: This three-hour workshop included instruction on scenario writing and on the use of standardized actors as patients and family members. Workshop leaders presented examples of commonly encountered clinical scenarios where difficult information is discussed. The session used experiential teaching techniques. Outcomes were measured by qualitative discussions and a questionnaire to demonstrate communication skills learned from the sessions. RESULTS: The workshop was well received by participants who consisted of educators attending the annual meeting of the Pediatric Academic Societies in May 2016. Evaluations revealed that 92% of participants agreed or strongly agreed that the workshop achieved the learning objectives. All participants believed that the workshop increased their knowledge, competency, and skills in teaching and facilitation as an educator, with 86% of participants planning to apply the skills toward curriculum development. The major themes that participants learned centered on facilitation skills as an educator and techniques on how to communicate during challenging family meetings (86% of comments). CONCLUSION: This train-the-educator workshop addresses a critical need in both palliative care and general medicine by enhancing the educators’ skills in designing and implementing a curriculum on communication skills of health care
providers using experiential techniques with formative feedback. The authors hope that by outlining the implementation of this three-hour interactive format, future educators will adapt and use this workshop as it works best for their learners.

https://www.ncbi.nlm.nih.gov/pubmed/28024994


OBJECTIVE: Palliative care for children is becoming an important subspecialty of healthcare. Although concurrent administration of curative and palliative care is recommended, timely referral to pediatric palliative care (PPC) services remains problematic. This literature review aims to identify barriers and recommendations for proper implementation of palliative care for children through the looking glass of PPC guidelines. METHOD: To identify studies on PPC guidelines, five databases were searched systematically between 1960 and 2015: Scopus, PubMed, PsycINFO, the Web of Science, and CINAHL. No restrictions were placed on the type of methodology employed in the studies. RESULTS: Concerning barriers, most of the papers focused on gaps within medical practice and the lack of evidence-based research. Common recommendations therefore included: training and education of healthcare staff, formation of a multidisciplinary PPC team, research on the benefits of PPC, and raising awareness about PPC. A small number of publications reported on the absence of clear guidance in PPC documents regarding bereavement care, as well as on the difficulties and challenges involved in multidisciplinary care teams. SIGNIFICANCE OF RESULTS: Our results indicate that a critical assessment of both the research guidelines and medical practice is required in order to promote timely implementation of PPC for pediatric patients.


RATIONALE: The decision of whether to initiate or forgo long-term ventilation for children with life-limiting conditions can be complex and impactful. Providers are responsible for helping families to understand the consequences of their options and guiding them through shared decision-making, but little has been published on how to do this. OBJECTIVES: To assess how directors of pediatric home ventilation programs facilitate shared decision-making with families facing decisions of whether to initiate or forgo long-term ventilation for their children with life-limiting conditions. In addition, to assess directors’ perspectives on these families’ decisional needs. METHODS: Purposeful recruiting of directors/co-directors of pediatric home ventilation programs at children’s hospitals was used. We performed semi-structured interviews using an open-ended interview guide developed de novo to assess their approach to informed, shared decision-making around long-term ventilation and their perspectives on these decisions. Qualitative data analysis was conducted using a thematic approach based on framework analysis in which thematic saturation was achieved. RESULTS: A sample of fifteen experienced physician directors across North America was interviewed. All (15/15) inform families of the potential benefits and burdens/risks of long-term ventilation for the child and of the option to forgo long-term ventilation. All stress to families the physical, emotional, and social impact of caring for a child using long-term ventilation on the family; twelve directors also highlight the financial impact. All recommend that decision-making around long-term ventilation should be interdisciplinary, initiated early, and not rushed; nine described their approach as guided by the family’s goals for the child and their family. All recommend that providers be transparent, candid, active listeners, and supportive. All directors believe that the family’s decision should be respected but vary in the extent to which they recommend an option to families. They described barriers to decision-making that stem from families, providers, and other sources. CONCLUSIONS: As providers who follow children using long-term ventilation, directors of pediatric home ventilation programs have perspectives regarding the decisional needs of these families
OBJECTIVE: Discussing the potential deterioration of a child who has a life-limiting condition has recognised benefits for future care, but can be challenging in a clinical context where uncertain illness trajectories are common. Existing research is restricted to indirect forms of evidence such as self-report data from clinicians and families. This study directly explores how discussions about deterioration are managed within actual paediatric palliative care consultations. METHODS: 9 consultations were video recorded in an Australian paediatric palliative care service. Each consultation involved the same paediatric palliative care specialist. Conversation analysis was used to identify and explore recurrent ways in which discussions about deterioration came to be realised. FINDINGS: The study identified two communicative practices used by a paediatric palliative care specialist that afforded opportunities to discuss deterioration: (1) soliciting the family’s agenda for the consultation; (2) initiating and maintaining topics where discussing deterioration is a relevant possibility. Across these different practices, a common feature was indirect initiation of discussions about deterioration. This approach made such discussions possible, but without mandating or even suggesting that such discussion must occur. CONCLUSIONS: These communicative practices balance the benefit of discussing deterioration against a recognised importance of allowing discussions to be directed by a child’s family. This was achieved by creating opportunities for discussing deterioration, without making such discussions necessary.


PURPOSE: To explore how nurses manage personal and professional boundaries in caring for seriously ill children and their families. DESIGN AND METHODS: Using a constructivist grounded theory approach, a convenience sample of 18 registered nurses from four practice sites was interviewed using a semi-structured interview guide. RESULTS: Nurses across the sites engaged in a process of maintaining integrity whereby they integrated two competing, yet essential, aspects of their nursing role - behaving professionally and connecting personally. When skillful in both aspects, nurses were satisfied that they provided high-quality, family-centered care to children and families within a clearly defined therapeutic relationship. At times, tension existed between these two aspects and nurses attempted to mitigate the tension. Unsuccessful mitigation attempts led to compromised integrity characterized by specific behavioral and emotional indicators. Successfully mitigating the tension with strategies that prioritized their own needs and healing, nurses eventually restored integrity. Maintaining integrity involved a continuous effort to preserve completeness of both oneself and one’s nursing practice. CONCLUSIONS: Study findings provide a theoretical conceptualization to describe the process nurses use in navigating boundaries and contribute to an understanding for how this specialized area of care impacts health care providers. PRACTICE IMPLICATIONS: Work environments can better address the challenges of navigating boundaries through offering resources and support for nurses’ emotional responses to caring for seriously ill children. Future research can further refine and expand the theoretical conceptualization of maintaining integrity presented in this paper and its potential applicability to other nursing specialties.


CONTEXT: Little is known about how parents of children with advanced cancer classify news they receive about their child’s medical condition. OBJECTIVE: To develop concepts of "good news" and
“bad news” in discussions of advanced childhood cancer from parent perspectives. METHODS: Parents of children with advanced cancer cared for at three children’s hospitals were asked to share details of conversations in the preceding three months that contained “good news” or “bad news” related to their child’s medical condition. We used mixed methods to evaluate parent responses to both open-ended and fixed-response items. RESULTS: Of 104 enrolled parents, 86 (83%) completed the survey. Six (7%) parents reported discussing neither good nor bad news, 18 (21%) reported only bad news, 15 (17%) reported only good news, and 46 (54%) reported both good and bad news (one missing response). Seventy-six parents (88%) answered free-response items. Descriptions of both good and bad news discussions consisted predominantly of “tumor talk” or cancer control. Additional treatment options featured prominently, particularly in discussions of bad news (42%). Child well-being, an important good news theme, encompassed treatment tolerance, symptom reduction, and quality of life. CONCLUSION: A majority of parents of children with advanced cancer report discussing both good and bad news in the preceding three months. Although news related primarily to cancer control, parents also describe good news discussions related to their child’s well-being. Understanding how parents of children with advanced cancer classify and describe the news they receive may enhance efforts to promote family-centered communication.


OBJECTIVE: The goal of this study was to explore nurse experiences in communication with children about spiritual topics in order to develop training in this area. BACKGROUND: Although spiritual care is essential in pediatric palliative care, few providers receive training about communication with ill children about spirituality. METHODS: Researchers developed a brief survey to prompt nurses to reflect on pediatric palliative care experiences that included spiritual discussions. Nurses attending training courses voluntarily submitted stories. Qualitative data were thematically analyzed by members of the research team, consisting of two researchers with expertise in palliative care, spirituality, and communication and two expert pediatric palliative care clinicians. RESULTS: Nurses’ spiritual conversations with children revealed that children question God and the reason for their illness, have a desire to talk about the afterlife as a way of understanding their limited lifespan, and to share descriptions of an afterlife, in these cases described as heaven. Nurses conveyed the importance of being present and engaging in spiritual communication with children. DISCUSSION: Communication training is needed and should prepare providers to respond to a child’s spiritual questioning, assist parents when the child initiates discussion about the afterlife, and help parent and child understand the spiritual meaning of their illness. Chaplains serve as spiritual care experts and can help train nurses to screen for spiritual distress, have greater competence in spiritual communication, and to collaborate with chaplains in care. Quality palliative care is incomplete without attention to spiritual care.


AIM: The ability to communicate serious news to patients and families in a caring and compassionate way is a critical skill for physicians. This study explores the impact of a novel communication skills workshop that included bereaved parents in role play on pediatric residents’ confidence to communicate serious news. METHODS: Following the workshop, pediatric residents were surveyed to assess their perceived efficacy of the educational intervention. The survey included anchored response and open-ended questions to yield qualitative and quantitative results. RESULTS: After completing the workshop, residents’ confidence in discussing goals, managing emotions, and expressing empathy all increased significantly. Residents reported that the inclusion of bereaved parents was beneficial since it made the experience more realistic. In addition, they believed their ability to communicate with patients and families had improved. CONCLUSIONS: Including bereaved parents in this communication skills workshop
improved the residents’ confidence in discussing serious topics and enhanced the reality of the experience.  
https://www.ncbi.nlm.nih.gov/pubmed/26602316


Shortly after I received my first R01 grant to study the health effects of caregiving, my sister and I became caregivers to our father. For the next 13 years, we helped him with activities of daily living (ADLs), accompanied him to doctors’ appointments, arranged for home health care, and finally for home hospice. At first, I was able to connect our assistance with ADLs, frustration with coordinating his care, and our psychological stress with my epidemiologic studies. My familiarity with the language of caregiving and long-term care helped us to navigate the medical and home care systems, and to be advocates for my father. However, as my father's health declined, I felt an increasing disconnect between my research and my experience: communicating with physicians and other care providers, responding to crises and conversations with my sister about placing our father in a nursing home were greater sources of stress than my father’s dementia. These discrepancies made me realize that I could help caregivers more by helping them to negotiate these challenges than through performing quantitative research. So I enrolled in a counseling psychology program. My manuscript will chronicle the ways that caregiving changed me; how my professional work did and did not help me as a caregiver; how the developmental and family theories that I am learning in my psychology classes have expanded my understanding of stressors facing adult child caregivers, and how this entire experience ties into generativity and Third Chapter careers that build on midlife experiences.  


At least 20 million children would benefit from Pediatric Palliative Care (PPC) annually, and 8 million children would need specialized PPC services. In the USA alone, more than 42,000 children 0-19 years died in 2013, fifty-five percent of them infants younger than 1 year. This article aims to critically review eight common assumptions, myths and barriers, which may hinder the implementation of PPC into the care of a child with advanced serious illnesses. Interdisciplinary PPC is about matching treatment to patient goals and is considered specialized medical care for children with serious illness. It is focused on relieving pain, distressing symptoms, and stress of a serious illness and appropriate at any age and at any stage, together with curative treatment. The primary goal is to improve quality of life for child and his or her family. Emerging evidence shows, that palliative care involvement results in improved quality of life as well as prolongation of life.  


Objective: To identify and understand the view of students regarding palliative care in paediatric oncology during a graduate programme. Methods: Exploratory research with a qualitative approach conducted in a school of nursing in Rio de Janeiro. Data were collected from September to November 2014, through semi-structured interviews with 20 students enrolled in the last period of a graduate programme. The data were subjected to thematic analysis. Results: The results produced two thematic units: the (un)preparedness of nursing students regarding palliative care in paediatric oncology and how the subject of palliative care in paediatric oncology is approached in the graduate programme. The students mentioned difficulties in providing this care and their lack of exposure to the topic during their graduate studies. They stated strategies to prepare for the provision of care, and talked about how the subject
should be addressed in their curricular programme. Conclusion: It is necessary to expand discussions on palliative care in paediatric oncology during the nurses' graduate programme.  


Perinatal palliative care programs seek to support parents expecting a baby diagnosed with a serious medical condition. Clinicians have increasingly recognized the importance of parental perspectives on the medical care mothers and their fetuses and live-born children receive, especially regarding factors influencing individual choices and knowledge of the medical community. We describe, using literature on trisomy 13 and trisomy 18, how information shared between parents and providers can improve perinatal counseling and family support.  


BACKGROUND: Preparedness to initiate end-of-life (EoL) discussions is a confronting and daunting task for all healthcare professionals. We conducted a group interview to explore healthcare professionals' experiences of preparing for EoL discussions with the patient and their family in a pediatric context. AIM: To identify what pediatric healthcare professionals consider important when preparing for an EoL discussion. METHODS: A qualitative design using a group interview. Two open-ended questions were asked: (1) How could preparedness to initiate EoL care discussions between healthcare professionals and the patient and family be enhanced? (2) What education resources/strategies could be developed to support preparation for EoL care discussions? SETTING/SUBJECTS: Healthcare professionals, including medical, nursing, and allied health professionals working in pediatric palliative care settings across Queensland, Australia. These settings included major tertiary hospitals, general practice, community, and nongovernment organizations. A convenience sample of 36 healthcare professionals consented to participate in the study. RESULTS: An analysis of the data identified seven themes that had relevance for preparing for an EoL discussion: communication, healthcare professional perspectives, interdisciplinary team role, patient and family perspectives, practical issues, addressing mistakes, and healthcare professional education. CONCLUSIONS: Pediatric healthcare professionals confirmed that gaps exist in preparing for an EoL discussion. The findings support a need for further research in two areas. First, a systematic review of interdisciplinary resources that are available to support healthcare professionals in preparing for EoL discussions is recommended. Second, evidence-based interdisciplinary interventions to support pediatric EoL discussions need to be developed and evaluated.  


Adult patients diagnosed with head and neck cancer (HNC) who may have contact with children in the home setting are at risk of experiencing distress because of embarrassing and challenging oral symptoms often associated with an HNC diagnosis and the side effects of required treatments. This article features a case study involving a patient diagnosed with HNC and details how oncology nurses can provide patients with HNC and their caregivers with resources and support.  


Neonatologists receive highly varied and largely inadequate training to acquire and maintain communication and palliative care skills. Neonatology fellows often need to give distressing news to
families and frequently face unique communication challenges. While several approaches to teaching these skills exist, practice opportunities through simulation and role play will likely provide the most effective learning.


OBJECTIVE: Life-limiting neuromuscular disease, such as some of the muscular dystrophies, are often diagnosed in early childhood: when death comes, commonly in the second or third decade of life, patients rarely have advance care plans in place or documented end-of-life care preferences. There is very limited literature concerning the discussions about end-of-life plans healthcare professionals have with young people affected by life-limiting neuromuscular diseases. The aim of this study was to investigate the views and experiences of healthcare professionals concerning having discussions about advance care plans and end-of-life care with teenagers and young adult patients affected by life-limiting neuromuscular diseases. METHODS: Semistructured interviews with a maximum variety sample of nine professionals involved in the care of young people with life-limiting neuromuscular diseases in one region of the UK. RESULTS: While recognising the inevitable progression of the conditions, there was no consensus among interviewees concerning best approaches to discuss end-of-life care plans. Several environmental and personal barriers were identified that lead to avoidance of the emotionally challenging and difficult conversations. CONCLUSIONS: Community-based professionals with well-established relationships with patients and families may be best placed to take the lead and coordinate discussions, but individual case-by-case preferences need to be carefully considered.


End of life care policy in the UK advocates open discussions between health professionals and patients as the end of life approaches. Despite well documented understanding of the progression of life-limiting neuromuscular diseases, the majority of patients affected by such conditions die without a formal end of life plan in place. We performed a systematic review to investigate conversations regarding end of life care between healthcare professionals and younger adult patients with life-limiting neuromuscular diseases. The search strategy included terms that focused on death and dying along with other factors that could impact length of life. The review found a very limited body of literature regarding end of life care conversations between young people affected by neuromuscular diseases and health professionals. The views and preferences of patients themselves have not been investigated. There is a shared reluctance of patients, family carers and healthcare professionals to initiate end of life care discussions. There are many factors that need to be investigated further in order to develop a consensus that would allow healthcare professionals to engage patients in end of life care conversations allowing them to face the end of their lives with appropriate plans in place.


BACKGROUND: Researchers report difficulties in conducting research with children and young people with life-limiting conditions or life-threatening illnesses and their families. Recruitment is challenged by barriers including ethical, logistical and clinical considerations. AIM: To explore how children and young people (aged 0-25 years) with life-limiting conditions or life-threatening illnesses and their families were identified, invited and consented to research published in the last 5 years. DESIGN: Systematic review. DATA SOURCES: MEDLINE, PsycINFO, Web of Science, Sciences Citation Index and SCOPUS were
searched for original English language research published between 2009 and 2014, recruiting children and young people with life-limiting conditions or life-threatening illness and their families. RESULTS: A total of 215 studies - 152 qualitative, 54 quantitative and 9 mixed methods - were included. Limited recruitment information but a range of strategies and difficulties were provided. The proportion of eligible participants from those screened could not be calculated in 80% of studies. Recruitment rates could not be calculated in 77%. A total of 31% of studies recruited less than 50% of eligible participants. Reasons given for non-invitation included missing clinical or contact data, or clinician judgements of participant unsuitability. Reasons for non-participation included lack of interest and participants’ perceptions of potential burdens. CONCLUSION: All stages of recruitment were under reported. Transparency in reporting of participant identification, invitation and consent is needed to enable researchers to understand research implications, bias risk and to whom results apply. Research is needed to explore why consenting participants decide to take part or not and their experiences of research recruitment. 


BACKGROUND: End-of-life (EOL) care intensity is known to vary by secular and geographic patterns. US physicians receive less aggressive EOL care than the general population, presumably the result of preferences shaped by work-place experience with EOL care. OBJECTIVE: We investigated occupation as a source of variation in EOL care intensity. METHODS: Across 4 states, we identified 660 599, nonhealth maintenance organization Medicare beneficiaries aged >/=66 years who died between 2004 and 2011. Linking death certificates, we identified beneficiaries with prespecified occupations: nurses, farmers, clergy, mortuary workers, homemakers, first-responders, veterinary workers, teachers, accountants, and the general population. End-of-life care intensity over the last 6 months of life was assessed using 5 validated measures: (1) Medicare expenditures, rates of (2) hospice, (3) surgery, (4) intensive care, and (5) in-hospital death. RESULTS: Occupation was a source of large variation in EOL care intensity across all measures, before and after adjustment for sex, education, age-adjusted Charlson Comorbidity Index, race/ethnicity, and hospital referral region. For example, absolute and relative adjusted differences in expenditures were US$9991 and 42% of population mean expenditure ( P < .001 for both). Compared to the general population on the 5 EOL care intensity measures, teachers (5 of 5), homemakers (4 of 5), farmers (4 of 5), and clergy (3 of 5) demonstrated significantly less aggressive care. Mortuary workers had lower EOL care intensity (4 of 5) but small numbers limited statistical significance. CONCLUSION: Occupations with likely exposure to child development, death/bereavement, and naturalistic influences demonstrated lower EOL care intensity. These findings may inform patients and clinicians navigating choices around individual EOL care preferences.


OBJECTIVES: This paper seeks to highlight from a UK perspective the current lack of a research evidence base in paediatric palliative care that has resulted in a paucity of available medicines with appropriate formulations (strength and dosage form) to provide symptom management for children with life-limiting illnesses and to raise awareness of this group of ‘therapeutic orphans’. Currently, clinicians have limited, often unsuitable medication choices for their paediatric palliative care patients, with little hope of moving away from the status quo. KEY FINDINGS: Most medicines used in children receiving palliative care are old and off-patent drugs, developed for and tested in an adult population. Many are not available in suitable formulations (dosage form and strength) for administration to children, and there are often no age-related profiles of adverse drug reactions or for safe dosing. SUMMARY: Existing regional paediatric palliative care networks and support organisations should lobby funding bodies and the academic community to support appropriate research for this group of therapeutic orphans. Support
must also be provided to pharmaceutical companies in the development of suitable products with appropriate formulations.


CONTEXT: Workforce productivity is poorly defined in health care. Particularly in the field of pediatric palliative care (PPC), the absence of consensus metrics impedes aggregation and analysis of data to track workforce efficiency and effectiveness. Lack of uniformly measured data also compromises the development of innovative strategies to improve productivity and hinders investigation of the link between productivity and quality of care, which are interrelated but not interchangeable. OBJECTIVES: To review the literature regarding the definition and measurement of productivity in PPC; to identify barriers to productivity within traditional PPC models; and to recommend novel metrics to study productivity as a component of quality care in PPC. METHODS: PubMed(R) and Cochrane Database of Systematic Reviews searches for scholarly literature were performed using key words (pediatric palliative care, palliative care, team, workforce, workflow, productivity, algorithm, quality care, quality improvement, quality metric, inpatient, hospital, consultation, model) for articles published between 2000 and 2016. Organizational searches of Center to Advance Palliative Care, National Hospice and Palliative Care Organization, National Association for Home Care & Hospice, American Academy of Hospice and Palliative Medicine, Hospice and Palliative Nurses Association, National Quality Forum, and National Consensus Project for Quality Palliative Care were also performed. Additional semistructured interviews were conducted with directors from seven prominent PPC programs across the U.S. to review standard operating procedures for PPC team workflow and productivity. RESULTS: Little consensus exists in the PPC field regarding optimal ways to define, measure, and analyze provider and program productivity. Barriers to accurate monitoring of productivity include difficulties with identification, measurement, and interpretation of metrics applicable to an interdisciplinary care paradigm. In the context of inefficiencies inherent to traditional consultation models, novel productivity metrics are proposed. CONCLUSIONS: Further research is needed to determine optimal metrics for monitoring productivity within PPC teams. Innovative approaches should be studied with the goal of improving efficiency of care without compromising value.


INTRODUCTION: Advance care planning (ACP), though recommended, has not been studied in adolescents with cystic fibrosis (CF). This quality improvement project engaged adolescents with advanced CF disease in ACP and assessed patient and CF provider attitudes and preferences regarding ACP discussions and tools. MATERIALS AND METHODS: Patients </=22 years with advanced CF (FEV1 </=40% predicted, >2 pulmonary exacerbations requiring IV antibiotics in 1 year, and/or use of home oxygen or non-invasive ventilation) were referred to the pediatric palliative care team (PC). After establishing rapport, ACP was discussed using Voicing My CHOICES: An Advanced Care Planning Guide (VMC). Patients completed a survey assessing attitudes and preferences around ACP. PC also led a training session for CF providers around ACP and VMC and provider attitudes were assessed via a pre- and post-training survey. RESULTS: Twelve patients (mean age 17.9 +/- 2.2 years) reviewed VMC and completed the ACP survey. The majority (83%) found ACP helpful. None felt it was harmful. All found VMC easy to understand and 90% felt it was appropriate for patients with CF. Of participating CF providers (pre-training, n = 6; post-training, n = 7), 83% found ACP worthwhile, but desired more training in this area. All found the training session useful and felt VMC was appropriate for patients with CF. DISCUSSION: Adolescents with advanced CF disease felt ACP was a positive experience and not
harmful. CF providers valued ACP, but desired more training. Both patients and providers felt that VMC was a useful, disease-appropriate tool. Pediatr Pulmonol. 2016;51:1304-1310. (c) 2016 Wiley Periodicals, Inc.
https://www.ncbi.nlm.nih.gov/pubmed/18980455


INTRODUCTION: End-of-life care is a critical issue for pediatric population with terminal illness to ensure the best possible quality of care for them and their families. A survey was conducted to identify the barriers and facilitators to provide pediatric end-of-life care. METHODS: A descriptive cross-sectional study was conducted at three tertiary centers providing end-of-life care in Jordan. Two hundred critical care nurses were surveyed (response rate 93%). RESULTS: Nurses reported moderate level of experience in all areas of delivering pediatric end-of-life care. The highest scoring of barriers respectively were patients-families barriers having deal with angry family member; health-care professional barriers multiple physicians, involved with one patient, who differ in opinion about the direction care, and where plan of care should go; and organizational barriers not available support person for the family. The highest scoring of facilitators respectively were of patients families facilitators having family members accept that the patient is dying; health-care professional-facilitators having a physician agrees about the direction of care, and organizational facilitators providing family members adequate time to be alone with the pediatric after he or she has died. CONCLUSION: Nurses perceived that patient-family, health-care professionals, and organizational related barriers and facilitators were had the most influence in providing of pediatric end-of-life care. Findings highlighted the need for additional education and support for pediatric staff, across professions, in providing pediatric end-of-life care. A pediatric end-of-life care team should be developed to assist in improving patients’ quality of care and increasing the awareness for the need for a standardized tool to evaluate the nursing competency level concerning pediatric end-of-life care.


BACKGROUND: Neonatology has made significant advances in the last 30 years. Despite the advances in treatments, not all neonates survive and a palliative care model is required within the neonatal context. Previous research has focused on the barriers of palliative care provision. A holistic approach to enhancing palliative care provision should include identifying both facilitators and barriers. A strengths-based approach would allow barriers to be addressed while also enhancing facilitators. The current study qualitatively explored perceptions of neonatal nurses about facilitators and barriers to delivery of palliative care and also the impact of the regional location of the unit. METHODS: The study was conducted at the Townsville Hospital, which is the only regional tertiary neonatal unit in Australia. Semi-structured interviews were conducted with a purposive sample of eight neonatal nurses. Thematic analysis of the data was conducted within a phenomenological framework. RESULTS: Six themes emerged regarding family support and staff factors that were perceived to support the provision of palliative care of a high quality. Staff factors included leadership, clinical knowledge, and morals, values, and beliefs. Family support factors included emotional support, communication, and practices within the unit. Five themes emerged from the data that were perceived to be barriers to providing quality palliative care. Staff perceived education, lack of privacy, isolation, staff characteristics and systemic (policy, and procedure) factors to impact upon palliative care provision. The regional location of the unit also presented unique facilitators and barriers to care. CONCLUSIONS: This study identified and explored facilitators and barriers in the delivery of quality palliative care for neonates in a regional tertiary setting. Themes identified suggested that a strengths-approach, which engages and amplifies facilitating factors while identified barriers are addressed or minimized, would be successful in supporting quality palliative care provision in the neonatal care setting. Study findings will be used to inform clinical education and practice.

PURPOSE: Attempts have been made within the literature to clarify the role and scope of speech-language pathologists (SLPs) within paediatric palliative care (PPC). As SLP literature regarding adult/geriatric populations is gaining traction, it is fitting to investigate the role of SLPs in the management of infants and children in end-of-life care. METHOD: Arksey and O’Malley’s (2005) scoping review method was utilised for searching multiple databases. Two database searches were undertaken. The first located literature in which SLP PPC intervention is specifically addressed. The second search utilised internationally recognised SLP scope of practice areas. Manual searching of reference lists was also utilised. RESULT: Themes identified included management of communication, feeding, upper-airway and oral health as well as the role of SLPs within a multidisciplinary PPC team. CONCLUSION: There is acknowledgement that SLPs have a role in PPC. However, there is little information identifying SLP involvement in the diagnosis and management of swallowing, cognition/communication, oral hygiene and upper airway issues. The available literature predominantly relies on limited adult palliative care research and does not address age-specific management approaches across the paediatric life-stage. Given an absence of SLP PPC guidelines, further research is warranted to explicitly define SLP scope of practice within this population.


BACKGROUND: The survival rate for infants born with life-threatening problems has improved greatly over the last few decades. Nevertheless, infants still die in neonatal intensive care units (NICUs) every day. Despite existing standards of care, some aspects of end-of-life care (EOLC) are still not delivered consistently. Little is known about how NICU nurses' individual experiences affect EOLC. PURPOSE: The purpose of this study was to explore, through lived and told stories, the affective, interactional, and meaning-related responses that NICU nurses have while caring for dying infants and their families. Coping strategies and changes in practice were also explored. METHODS: Thirty-six members of the National Association of Neonatal Nurses submitted written narratives about an EOLC experience during which the nurse experienced strong emotions. FINDINGS: Narrative analysis revealed many affective responses, but 3 were the most frequent: responsibility, moral distress, and identification. Coping methods included healthy and less healthy strategies, such as colleague support, informal and formal debriefing, practicing intentional gratefulness, avoidance, and compartmentalization. Changes in practice identified were universally described as professional growth through the use of reflective practice. IMPLICATIONS FOR PRACTICE & RESEARCH: Educators should discuss the range of emotions experienced by caregivers related to EOLC and healthy coping strategies and encourage the use of reflective practice as a facilitator of professional growth. Nurse leaders should promote supportive environments in NICUs and ensure debriefing opportunities for nurses who have recently cared for a dying infant. Future research should focus on formulating interventions to utilize debriefing with NICU nurses and perhaps the development of EOLC mentors.


BACKGROUND: Provision of language services in pediatric hospice enables nurses to communicate effectively with patients who have limited English proficiency. Language barriers contribute to ethnic disparities in health care. While language service use corresponds with improved patient comprehension of illness and care options, we lack an understanding of how the nurse work environment affects the provision of these services. METHODS: Data were obtained from the 2007 National Home and Hospice Care Survey and included a study sample of 1251 pediatric hospice agencies. Variable selection was
guided by structural contingency theory, which posits that organizational effectiveness is dependent upon how well an organization’s structure relates to its context. Using multivariate logistic regression, we analyzed the extent to which nursing unit environment predicted provision of translation services and interpreter services. RESULTS: The majority of hospices provided translation services (74.9 %) and interpreter services (87.1 %). Four variables predicted translation services: registered nurse (RN) unit size, RN leadership, RN medical expertise, and for-profit status. RN medical expertise and having a safety climate within the hospice corresponded with provision of interpreter services. CONCLUSIONS: Findings indicate that nursing unit environment predicts provision of language services. Hospices with more specialized RNs and a stronger safety climate might include staffs who are dedicated to best care provision, including language services. This study provides valuable data on the nurse work environment as a predictor of language services provision, which can better serve patients with limited English proficiency and ultimately reduce ethnic disparities in end-of-life care for children and their families.


Priority setting for healthcare research is as important as conducting the research itself because rigorous and systematic processes of priority setting can make an important contribution to the quality of research. This project aimed to prioritise clinical therapeutic uncertainties in paediatric pain and palliative care in order to encourage and inform the future research agenda and raise the profile of paediatric pain and palliative care in the United Kingdom. Clinical therapeutic uncertainties were identified and transformed into patient, intervention, comparison and outcome (PICO) format and prioritised using a modified Nominal Group Technique. Members of the Clinical Studies Group in Pain and Palliative Care within National Institute for Health Research (NIHR) Clinical Research Network (CRN)-Children took part in the prioritisation exercise. There were 11 clinically active professionals spanning across a wide range of paediatric disciplines and one parent representative. The top three research priorities related to establishing the safety and efficacy of (1) gabapentin in the management of chronic pain with neuropathic characteristics, (2) intravenous non-steroidal anti-inflammatory drugs in the management of post-operative pain in pre-schoolers and (3) different opioid formulations in the management of acute pain in children while at home. Questions about the long-term effect of psychological interventions in the management of chronic pain and various pharmacological interventions to improve pain and symptom management in palliative care were among the ‘top 10’ priorities. The results of prioritisation were included in the UK Database of Uncertainties about the Effects of Treatments (DUETS) database. Increased awareness of priorities and priority-setting processes should encourage clinicians and other stakeholders to engage in such exercises in the future.


BACKGROUND: Previous work on difficult relationships between patients and physicians has largely focused on the adult primary care setting and has typically held patients responsible for challenges. Little is known about experiences in pediatrics and more serious illness; therefore, we examined difficult relationships between parents and physicians of children with cancer. METHODS: This was a cross-sectional, semistructured interview study of parents and physicians of children with cancer at the Dana-Farber Cancer Institute and Boston Children's Hospital (Boston, Mass) in longitudinal primary oncology relationships in which the parent, physician, or both considered the relationship difficult. Interviews were audiotaped, transcribed, and subjected to a content analysis. RESULTS: Dyadic parent and physician interviews were performed for 29 relationships. Twenty were experienced as difficult by both parents and physicians; 1 was experienced as difficult by the parent only; and 8 were experienced as difficult by the physician only. Parent experiences of difficult relationships were characterized by an impaired therapeutic alliance with physicians; physicians experienced difficult relationships as demanding. Core underlying issues included problems of connection and understanding (n = 8), confrontational parental advocacy (n
(n = 16), mental health issues (n = 2), and structural challenges to care (n = 3). Although problems of connection and understanding often improved over time, problems of confrontational advocacy tended to solidify. Parents and physicians both experienced difficult relationships as highly distressing.

CONCLUSIONS: Although prior conceptions of difficult relationships have held patients responsible for challenges, this study has found that difficult relationships follow several patterns. Some challenges, such as problems of connection and understanding, offer an opportunity for healing. However, confrontational advocacy appears especially refractory to repair; special consideration of these relationships and avenues for repairing them are needed. Cancer 2017;123:675-681. (c) 2016 American Cancer Society. https://www.ncbi.nlm.nih.gov/pubmed/27727442


BACKGROUND: More attention is being paid to the wellbeing of staff working in stressful situations. However, little is known about staff experience of providing end-of-life care to children within a hospice setting. This study aims to explore the experiences of care team staff who provide end-of-life care within a children’s hospice. METHODS: Qualitative research incorporating interviews and a focus group. Data were analysed using thematic analysis. Purposeful sampling led to a total of 15 care team staff recruited from a children’s hospice offering palliative and specialist care to life-limited children and young people. RESULTS: The hospice setting provides a model of excellence in supporting staff and mitigating challenging aspects of their role, which includes peer/organisational support, and regular ongoing training in key aspects of children’s palliative care. Key recommendations for improving their experience included advanced communication training and knowledge sharing with other children’s palliative care specialists within the acute setting. CONCLUSIONS: Service and policy initiatives should encourage open, informal peer/organisational support among the wider children’s palliative care sector. Further research should focus on paediatric palliative care education, particularly in relation to symptom management and communication at end-of-life, harnessing the expertise and breadth of knowledge that could be shared between children’s hospices and hospital settings. https://www.ncbi.nlm.nih.gov/pubmed/28193270


BACKGROUND: Staff who provide end-of-life care to children not only have to deal with their own sense of loss but also that of bereaved families. There is a dearth of knowledge on how they cope with these challenges. AIM: The aim of this review is to explore the experiences of healthcare professionals who provide end-of-life care to children in order to inform the development of interventions to support them, thereby improving the quality of paediatric care for both children and their families. DATA SOURCES: Searches included CINAHL, MEDLINE, Web of Science, EMBASE, PsychINFO and The Cochrane Library in June 2015, with no date restrictions. Additional literature was uncovered from searching reference lists of relevant studies, along with contacting experts in the field of paediatric palliative care. DESIGN: This was a systematic mixed studies review. Study selection, appraisal and data extraction were conducted by two independent researchers. Integrative thematic analysis was used to synthesise the data. RESULTS: The 16 qualitative, 6 quantitative and 8 mixed-method studies identified included healthcare professionals in a range of settings. Key themes identified rewards and challenges of providing end-of-life care to children, the impact on staff’s personal and professional lives, coping strategies and key approaches to help support staff in their role. CONCLUSION: Education focusing on the unique challenges of providing end-of-life care to children and the importance of self-care, along with timely multidisciplinary debriefing, are key strategies for improving healthcare staff’s experiences, and as such the quality of care they provide. https://www.ncbi.nlm.nih.gov/pubmed/27129677

BACKGROUND: Automated external defibrillators can be life-saving in out-of-hospital cardiac arrest. OBJECTIVE: Our aim was to review our experience of prescribing automated external defibrillators for children at increased risk of sudden arrhythmic death. METHODS: We reviewed all automated external defibrillators issued by the Scottish Paediatric Cardiac Electrophysiology Service from 2005 to 2015. All parents were given resuscitation training according to the Paediatric Resuscitation Guidelines, including the use of the automated external defibrillator. RESULTS: A total of 36 automated external defibrillators were issued to 36 families for 44 children (27 male). The mean age at issue was 8.8 years. Diagnoses at issue included long QT syndrome (50%), broad complex tachycardia (14%), hypertrophic cardiomyopathy (11%), and catecholaminergic polymorphic ventricular tachycardia (9%). During the study period, the automated external defibrillator was used in four (9%) children, and in all four the automated external defibrillator correctly discriminated between a shockable rhythm - polymorphic ventricular tachycardia/ventricular fibrillation in three patients with one or more shocks delivered - and non-shockable rhythm - sinus rhythm in one patient. Of the three children, two of them who received one or more shocks for ventricular fibrillation/polymorphic ventricular tachycardia survived, but one died as a result of recurrent torsades de pointes. There were no other deaths. CONCLUSION: Parents can be taught to recognise cardiac arrest, apply resuscitation skills, and use an automated external defibrillator. Prescribing an automated external defibrillator should be considered for children at increased risk of sudden arrhythmic death, especially where the risk/benefit ratio of an implantable defibrillator is unclear or delay to defibrillator implantation is deemed necessary.


BACKGROUND: Research into the key themes and concepts of quality of life (QOL) relevant to the end-of-life (EOL) care of pediatric cancer patients in the Japanese context is imperative. OBJECTIVE: This study aimed at identifying the key items and constructive concepts of QOL at EOL of pediatric cancer patients. DESIGN: In 2015, pediatricians and nurses were recruited from 163 pediatric oncology treatment facilities in Japan. The questionnaire was developed on the basis of a previous qualitative study. Items that were rated as "very important" or "important" by at least 80% of the respondents were considered as "common and important" QOL items. Exploratory factor analysis was performed to conceptualize QOL of the pediatric cancer patients during EOL care. RESULTS: A total of 157 pediatricians and 270 nurses participated in this study. Fifty-five items were refined to 35 "common and important" QOL items. On factor analysis, 12 domains (containing 29 items) were identified: playing and learning; fulfilling wishes; spending time with family; receiving relief from physical and psychological suffering; making many wonderful memories; having a good relationship with the medical staff; having a peaceful death in the presence of family; spending time with a minimum of medical treatment; living one's life as usual; spending time in a calm hospital environment; being oneself; and having a close family. CONCLUSIONS: Although the respondents in this study were medical care providers rather than the patients or their family members, findings should help medical staff provide better palliative care to Japanese pediatric cancer patients.


OBJECTIVE: This mixed-methods study set in the West Midlands region of the UK demonstrates the effectiveness of Q methodology in examining general practitioners' (GPs') perception of their role in children's oncology palliative care. METHODS: Using data obtained from the analysis of semistructured interviews with GPs who had cared for a child receiving palliative care at home and bereaved parents, 50 statements were identified as representative of the analysis findings. 32 GPs with a non-palliative child with cancer on their caseload were asked to rank the statements according to their level of agreement/disagreement on a grid. They were then asked to reflect and comment on the statements.
they most and least agreed with. The data were analysed using a dedicated statistical software package for Q analysis PQMethod V.2.20 (Schmolck 2012). A centroid factor analysis was undertaken initially with 7 factors then repeated for factors 1-6. Varimax and manual flagging was then completed. RESULTS: 4 shared viewpoints were identified denoting different GP roles: the GP, the compassionate practitioner, the team player practitioner and the pragmatic practitioner. In addition consensus (time pressures, knowledge deficits, emotional toll) and disagreement (psychological support, role, experiential learning, prior relationships) between the viewpoints were identified and examined. CONCLUSIONS: Q methodology, used for the first time in this arena, identified 4 novel and distinct viewpoints reflecting a diverse range of GP perspectives. Appropriately timed and targeted GP education, training, support, in conjunction with collaborative multiprofessional working, have the potential to inform their role and practice across specialities.


BACKGROUND: Nurse practitioners (NP) are relatively new in Australia with national registration achieved in 2010. Most NP-related literature is about establishing models and scope of practice. This paper reports on the establishment and 12-month evaluation of an NP model of care, between inpatient and community palliative care services, developed to coordinate client care between hospital and home. AIM: To enhance patient outcomes, in hospital or home; to enhance professional relationships between services and facilitate effective discharges and admissions between services. DESIGN AND SETTING: Both services worked together to develop an evaluation framework, based on agreed key performance indicators. RESULTS: The NP model contributed to earlier discharges from hospital and fewer hospital admissions for those being cared for at home. There are developing opportunities to strengthen professional relationships through clinical and educational collaboration. CONCLUSION: The model has benefited both patient care and clinical cooperation between services.


BACKGROUND: Increasing numbers of families are requesting active supportive management for their child with spinal muscular atrophy type 1 (SMA1), leading to longer survival and greater prevalence of affected children. Strong opinions exist among physicians for and against the provision of care measures prolonging life. OBJECTIVE: To describe current practice in the care of SMA1 in Canada, and explore the factors underlying inter-physician variability. METHODS: A cross-sectional survey of Canadian hospital-based pediatric neurologists and pediatric respirologists was performed in 2015. Odds ratios and 95% confidence intervals were calculated to compare proportions between groups. RESULTS: There was a 54% completion rate (99 physicians). Over half of participants believed that a disease modifying therapy was likely within 10 years. Quebec respirologists were 50 times less likely to offer long-term non-invasive ventilation (NIV) than respirologists in other provinces (OR 50.6, 95% CI 2.4-1075.3), and 20 times less likely to discuss tracheostomy with families (OR 20.4, 95% CI 2.0-211.8). High raters of perceived happiness of affected children were more likely to find NIV an acceptable measure for acute (OR 6.7, 95% CI 1.7-26.0) and chronic (OR 13.7, 95% CI 4.0-46.4) respiratory failure and prophylactic use (OR 5.8, 95% CI 2.2-15.6). CONCLUSION: Physician knowledge, opinions, subjective perception of child happiness, and regional factors, all influence physicians’ practices and the shared decision-making process. Parents may not be informed or offered all the services available to their child. Knowledge translation initiatives are needed to enhance SMA1 care. Pediatr Pulmonol. 2017;52:662-668. (c) 2016 Wiley Periodicals, Inc.

Reports focusing on biomedical principlism and the role of anaesthesiologists in palliative care are rare. We present the case of a newborn with multiple craniofacial anomalies and a diagnosis of ADAM "sequence," in which surgical removal of placental adhesions to the dura mater and the correction of meningocele was not indicated due to the very short life expectancy. After 48 hours, the odor from the placenta indicted a necrotic process, which prevented the parents from being close to the child and increased his isolation. Urgent surgery was performed, after which the newborn was transported to the ICU and intubated under controlled mechanical ventilation. The patient died a week later. The principles of beneficence, nonmaleficence, justice, and respect for autonomy are simultaneously an inspiratory and regulatory framework for clinical practice. Although only necessary procedures are defended, which suggests a position contrary to invasive interventions at the end of life, sometimes they are the best palliative measures that can be taken in cases like the one described here.


A lack of knowledge and skills in pediatric palliative care may create hesitation in caring for children with serious life-threatening conditions and their families. Our research examined the effectiveness of pediatric palliative care training for pediatric clinicians. A pretest-posttest study provided educational training in pediatric palliative care to pediatric clinicians and used a pretest and a posttest to assess outcomes. Fifty pediatric clinicians attended this research with 83.3% response rate. After training, participants reported significantly increased confidence in a variety of areas, including providing emotional support to clinicians, personal knowledge, skills, and communication; ethical and legal concerns; and providing emotional support to dying children and their families. Results showed a significant main effect of training on confidence levels (p < .000). This suggests that education can effectively boost pediatric clinicians' confidence regarding providing pediatric palliative care and therefore should regularly be provided to clinicians.


BACKGROUND: The use of simulation-based medical/nursing teaching is increasingly widespread. Simulation-based teaching offers an immersive learning experience where professionals can practice communication and practical skills in a safe, authentic environment. We designed a paediatric palliative simulation study day primarily aimed at nursing staff who manage these patients in the community/hospice. We believe this is the first of its kind in the UK. AIMS: To establish whether attendance at a paediatric palliative simulation study day improved confidence and knowledge in management of common and/or difficult situations in palliative care. METHOD: Health professionals working at local paediatric hospices or in associated specialties to palliative care were invited to attend the free 1-day course. 5 scenarios were developed by experienced health professionals working in paediatric palliative care. On the day, participants were asked to complete a questionnaire to check basic demographic data, confidence levels and knowledge (50 true/false questions). Following participation/observation of 5 scenarios, they again completed the same questionnaire regarding confidence levels and knowledge. Results were analysed with Excel and XLStat using basic demographic data and Wilcoxon signed rank two-tailed test. RESULTS: 57 healthcare workers participated in 5 study days. 81% (n=47) professionals described themselves as working primarily in palliative care. Only 35% (n=20) had previously experienced simulation. Based on confidence questions, attendees felt more confident in managing specific palliative scenarios (p<0.0001). Based on true/false questions prestudy and poststudy day, 86% (n=49) of participants improved their knowledge. The median improvement score for the cohort was 3 (p<0.0001). CONCLUSIONS: The study demonstrated a significant improvement in confidence and knowledge following the simulation course. This supports further time/financial investment in developing this type of study day. Simulation is a useful teaching method.
adjunct in paediatric palliative care. The course also provides a valuable opportunity for professionals to network and discuss/share experiences.


OBJECTIVES: The benefits of non-invasive ventilation (NIV) have been clearly demonstrated in pediatrics. In palliative care, NIV can improve the level of comfort and quality of life and can decrease dyspnea. The objective was to survey pediatricians’ opinions and practices regarding NIV in palliative care in France.

DESIGN: A mail survey was conducted among pediatric pneumologists, intensivists and palliative medicine consultants from February 2015 to March 2015. RESULTS: In case of acute respiratory failure, 84% of the responding practitioners found NIV appropriate in do-not-intubate (DNI) children, while only 35% of them found it appropriate in comfort-measures-only (CMO) children (P<0.0001). In case of progressive respiratory failure, 68% of the responders found NIV appropriate in DNI children, while only 30% in CMO children (P<0.05). The major criterion for initiating NIV in pediatric palliative care was the presence of dyspnea. In pediatric palliative care, the efficacy of NIV was evaluated primarily clinically in terms of the improvement of the child’s comfort level, as well as the child’s and family’s satisfaction. Hypercapnia and desaturation were rarely measured to initiate NIV or to assess its efficacy. Sixty percent of the responding practitioners indicated that referral to NIV was anticipated with children and family before acute events or end-of-life occurred. CONCLUSION: French pediatricians habitually use NIV for management of acute or progressive respiratory symptoms in DNI children. In CMO children, a majority of responding practitioners find NIV inappropriate. In palliative care, the indications for and efficacy of NIV are evaluated based on clinical criteria and rarely on gasometric criteria.


OBJECTIVES: Rudeness is routinely experienced by medical teams. We sought to explore the impact of rudeness on medical teams’ performance and test interventions that might mitigate its negative consequences. METHODS: Thirty-nine NICU teams participated in a training workshop including simulations of acute care of term and preterm newborns. In each workshop, 2 teams were randomly assigned to either an exposure to rudeness (in which the comments of the patient’s mother included rude statements completely unrelated to the teams’ performance) or control (neutral comments) condition, and 2 additional teams were assigned to rudeness with either a preventative (cognitive bias modification [CBM]) or therapeutic (narrative) intervention. Simulation sessions were evaluated by 2 independent judges, blind to team exposure, who used structured questionnaires to assess team performance. RESULTS: Rudeness had adverse consequences not only on diagnostic and intervention parameters (mean therapeutic score 3.81 +/- 0.36 vs 4.31 +/- 0.35 in controls, P < .01), but also on team processes (such as information and workload sharing, helping and communication) central to patient care (mean teamwork score 4.04 +/- 0.34 vs 4.43 +/- 0.37, P < .05). CBM mitigated most of these adverse effects of rudeness, but the postexposure narrative intervention had no significant effect. CONCLUSIONS: Rudeness has robust, deleterious effects on the performance of medical teams. Moreover, exposure to rudeness debilitated the very collaborative mechanisms recognized as essential for patient care and safety. Interventions focusing on teaching medical professionals to implicitly avoid cognitive distraction such as CBM may offer a means to mitigate the adverse consequences of behaviors that, unfortunately, cannot be prevented.

Background. There is a need for increased palliative care training during pediatric residency. Objective. In this pilot study, we created a comprehensive experiential model to teach palliative care skills to pediatric residents. Our Comfort Care Modules (CCMs) address pediatric palliative care (PPC) topics of breaking bad news, dyspnea, anxiety, pain management, and the dying child. We also evaluated a scoring system and gathered qualitative data. Methods. The CCMs are part of the University of California San Diego pediatric residency’s second-year curriculum. Comparisons were made for statistical trends between residents exposed to the modules (n = 15) and those not exposed (n = 4). Results. Nineteen of 36 residents (52%) completed surveys to self-rate their preparedness, knowledge, and confidence about PPC before and after the intervention. Resident scores increased in all areas. All improvements reached statistical significance except confidence when breaking bad news. Overall, the resident feedback about the CCMs was positive. Conclusions. This study demonstrates that the CCMs can be performed effectively in an academic setting and can benefit residents’ self-perception of preparedness, confidence, and knowledge about pediatric palliative care. In the future, we plan to implement the modules on a larger scale. We encourage their use in interprofessional settings and across institutions.


When a life is lost or severely impaired during childbirth, the midwife and obstetrician involved may experience feelings of guilt in the aftermath. Through three empirical cases, the paper examines the sense of guilt in the context of the current patient safety culture in healthcare where a blame-free approach is promoted in the aftermath of adverse events. The purpose is to illustrate how healthcare professionals may experience guilt without being at fault after adverse events, and Gamlund’s theory on forgiveness without blame is used as the theoretical framework for this analysis. Philosophical insight has proven to be a useful resource in dealing with psychological issues of guilt and Gamlund’s view on error and forgiveness elucidates an interesting dilemma in the field of traumatic events and medical harm in healthcare, where healthcare professionals experience that well-intended actions may cause injury, harm or even death to their patients. Failing to recognise and acknowledge guilt or guilty feelings may preclude self-forgiveness, which could have a negative impact on the recovery of midwives and obstetricians after adverse events. Developing and improving support systems for healthcare professionals is a multi-factorial task, and the authors suggest that the narrow focus on medico-legal and patient safety perspectives is complemented with moral philosophical perspectives to promote non-judgemental recognition and acknowledgement of guilt and of the fallible nature of medicine.


BACKGROUND: Primary care physicians (General Practitioners (GPs)) play a pivotal role in providing end of life care (EoLC). However, many lack confidence in this area, and the quality of EoLC by GPs can be problematic. Evidence regarding educational needs, learning preferences and the acceptability of evaluation methods is needed to inform the development and testing of EoLC education. This study therefore aimed to explore GPs’ EoLC educational needs and preferences for learning and evaluation.

METHODS: A qualitative focus group study was conducted with qualified GPs and GP trainees in the UK. Audio recordings were transcribed and analysed thematically. Expert review of the coding frame and dual coding of transcripts maximised rigour. RESULTS: Twenty-eight GPs (10 fully qualified, 18 trainees) participated in five focus groups. Four major themes emerged: (1) why education is needed, (2) perceived educational needs, (3) learning preferences, and (4) evaluation preferences. EoLC was perceived as emotionally and clinically challenging. Educational needs included: identifying patients for palliative care; responsibilities and teamwork; out-of-hours care; having difficult conversations; symptom management; non-malignant conditions; and paediatric palliative care. Participants preferred learning
through experience, working alongside specialist palliative care staff, and discussion of real cases, to
didactic methods and e-learning. 360 degrees appraisals and behavioural assessment using videoing or
simulated interactions were considered problematic. Self-assessment questionnaires and patient
family outcome measures were acceptable, if used and interpreted correctly. CONCLUSIONS: GPs
require education and support in EoLC, particularly the management of complex clinical care and
counselling. GPs value mentoring, peer-support, and experiential learning alongside EoLC specialists
over formal training.


Shorey, S., B. Andre and V. Lopez (2017). "The experiences and needs of healthcare professionals

BACKGROUND: Globally, perinatal death is on a decline. However, its impact on the healthcare
profession is huge. The existing literature focuses on examining perinatal death from parents’
perspectives and patient death from the perspectives of nurses and a few doctors in critical care,
ocology, and neonatology in the West. Due to the unique setting of maternity units where death is not
routinely anticipated, as well as distinctive socio-cultural views surrounding death, there is a need to
comprehensively review literature examining the impact of perinatal death on the perspectives of
healthcare professionals working in maternity units. OBJECTIVES: To examine available literature on the
needs and experiences of healthcare professionals working in maternity units who have experienced
perinatal death. DESIGN: A scoping review of published and unpublished data. DATA SOURCES: A
systematic literature search from 1st January 1996 to 5th August 2016 was made in the following
Library, Joanna Briggs Institute Library of Systematic Reviews, York Centre for Reviews and
Dissemination, Open Grey, ProQuest Dissertation and Theses, and Mednar were reviewed for grey
literature. A hand search of the reference lists of the included papers was performed. REVIEW
METHODS: Based on the pre-set inclusion criteria, 1519 articles were screened for their titles and
abstracts. Eighty-five full-text papers were reviewed, resulting in 30 papers included for this review.
The data were extracted and cross-checked between the reviewers. Any discrepancy between the authors’
views would be discussed with a third reviewer until consensus was reached. Thematic analysis was
used to categorise the results into themes. RESULTS: Two major themes emerged from the review: the
experiences and needs of healthcare professionals. Six subthemes emerged from the experiences of
healthcare professionals: 1) psychological impact, 2) physical impact, 3) positive feelings, 4) coping
strategies, 5) personal factors influencing the experience, and 6) cultural factors influencing the
experience. Three subthemes including 1) social support, 2) training and education, and 3) other needs
explained the needs of healthcare professionals. Studies focusing on the experiences and needs of
physicians were scarce. CONCLUSIONS: Perinatal death has a profound impact on the psychological
and physical wellbeing of healthcare professionals. They have unmet needs that need to be addressed.
Though they use internal and external resources to combat their stress, institutional support
acknowledging their stress and their needs is essential. Culturally-sensitive education and training are
needed to provide support to these professionals.


The connection between palliative care and HIV infection has deep and wide roots in the United States
that go back to the time when many gay men in the early 1980s were dying from a disease we knew little
about, and there was no way to help but to alleviate symptoms in hospice and end of life centers across
the United States. More individuals (adults and children), families, and communities attribute the success
of antiretroviral therapies and other therapeutic approaches to advancing quality of life and life itself
today. The identity of HIV, like many ‘life-threatening illness with no cure’ has evolved as a ‘chronic’
condition with a longer time period to address physical, social, and emotional experiences that may
concern those living with HIV infection. Chronic conditions create an opportunity for healthcare providers
from all types of disciplines to rethink and retool their knowledge and skills, to have conversations with
those affected by HIV infection as to what they would ideally want in addressing their care needs; care needs that are now complicated by comorbid conditions of aging and healthcare reimbursement that uniquely intersect with HIV infection. This chapter addresses the current relevance of palliative care in HIV history, both nationally and internationally, and offers ideas for health professionals to use a multidisciplinary integration of knowledge to not just cure but align ‘cure and care’ toward healing action while being present to others from their perspective and values.


BACKGROUND: Medical trainees consistently report suboptimal instruction and poor self-confidence in communication skills. Despite this deficit, few established training programs provide comprehensive, pediatric-specific communication education, particularly in the provision of "bad news." To our knowledge, no programs currently use bereaved parent educators to facilitate communication training for pediatric subspecialty trainees. PROCEDURE: The authors designed and implemented a pilot communication training seminar in which bereaved parent educators and faculty facilitators led small groups in interactive, role-play scenarios. Surveys incorporating a retrospective preprogram assessment item to account for response-shift bias were used to assess short- and long-term changes in trainee comfort with delivering "bad news." RESULTS: Fifteen pediatric fellowship trainees participated in the communication seminar; complete data were available for 12 participants. After accounting for response-shift bias, participants reported significant improvement in overall preparedness, breaking bad news to a patient and family, and including the adolescent or young adult patient in conversations. Additionally, participants reported a significant improvement in their ability to address a patient and family's need for information, emotional suffering at the end of life (EOL), if and when a patient should be included in the conversation, and EOL care decisions. The participant’s self-perceived improvement in comfort and preparedness persisted over time. CONCLUSIONS: Communication training for pediatric subspecialty trainees using bereaved parent educators is feasible and effective. Both medical trainee and bereaved parent participants benefited from involvement in this pilot study. Further iterations of this training will be modified to assess objective measures of improvement in trainees’ communication skills.

Spalding, J. and S. Yardley (2016). '"The nice thing about doctors is that you can sometimes get a day off school': an action research study to bring lived experiences from children, parents and hospice staff into medical students' preparation for practice." BMJ Support Palliat Care 6(4): 459-464.

Patient and public involvement in healthcare is important to ensure services meet their needs and priorities. Increasingly, patient experiences are being used to educate healthcare professionals. The potential contribution to medical education of children and parents using hospice services has not yet been fully explored. OBJECTIVES: (1) To explore perceptions of what medical students must learn to become ‘good doctors’ among children, parents and staff in a hospice. (2) To collaborate with children/parents and staff to develop educational materials based on their lived experiences for medical students. (3) To assess feasibility of student-led action research in a children’s hospice to develop research skills. METHODS: Prospective ethical approval received. Volunteer children (n=7), parents (n=5) and staff (n=6) were recruited from a children’s hospice. Data were generated in audio-recorded semistructured focus groups, individual interviews and/or activity workshops. Participants discussed what newly qualified doctors’ needed to care for children with life-limiting conditions. Audio data were transcribed and combined with visual data for thematic analysis. Findings were refined by participant feedback. This paper presents thematic findings and educational material created from the project. RESULTS: Thematic analysis identified six learning themes: (1) treat children as individuals; (2) act as a person before being a doctor; (3) interpersonal communication; (4) appreciate the clinical environment; (5) learn from children, parents and other staff; (6) how to be a doctor as part of a team. The student researcher successfully developed qualitative research skills, coproducing materials with participants for
sharing learning derived from lived experiences. CONCLUSIONS: All participants were willing and able to make valuable contributions, and believed that this was a worthwhile use of time and effort. Further work is required to understand how best to integrate the experiences of children in hospices into medical education.


In order to gain more insight on the influence of ethnic diversity in paediatric cancer care, the perspectives of care providers were explored. Semi-structured interviews were conducted among 12 paediatric oncologists and 13 nurses of two different paediatric oncology wards and were analysed using a framework method. We found that care providers described the contact with Turkish and Moroccan parents as more difficult. They offered two reasons for this: (1) language barriers between care provider and parents hindered the exchange of information; (2) cultural barriers between care provider and parents about sharing the diagnosis and palliative perspective hindered communication. Care providers reported different solutions to deal with these barriers, such as using an interpreter and improving their cultural knowledge about their patients. They, however, were not using interpreters sufficiently and were unaware of the importance of eliciting parents’ perspectives. Communication techniques to overcome dilemmas between parents and care providers were not used and care providers were unaware of stereotypes and prejudice. Care providers should be offered insight in cultural barriers they are unaware of. Training in cultural competence might be a possibility to overcome manifest barriers.


OBJECTIVE: To examine burnout prevalence among California neonatal intensive care units (NICUs) and to test the relation between burnout and healthcare-associated infection (HAI) rates in very low birth weight (VLBW) neonates. STUDY DESIGN: Retrospective observational study of provider perceptions of burnout from 2073 nurse practitioners, physicians, registered nurses and respiratory therapists, using a validated four-item questionnaire based on the Maslach Burnout Inventory. The relation between burnout and HAI rates among VLBW (<1500 g) neonates from each NICU was evaluated using multi-level logistic regression analysis with patient-level factors as fixed effects. RESULTS: We found variable prevalence of burnout across the NICUs surveyed (mean 25.2+/−10.1%). Healthcare-associated infection rates were 8.3+/−5.1% during the study period. Highest burnout prevalence was found among nurses, nurse practitioners and respiratory therapists (non-physicians, 28+/−11% vs 17+/−19% physicians), day shift workers (30+/−3% vs 25+/−4% night shift) and workers with 5 or more years of service (29+/−2% vs 16+/−6% in fewer than 3 years group). Overall burnout rates showed no correlation with risk-adjusted rates of HAI (r=−0.133). Item-level analysis showed positive association between HAI and perceptions of working too hard (odds ratio 1.15, 95% confidence interval 1.04-1.28). Sensitivity analysis of high-volume NICUs suggested a moderate correlation between burnout prevalence and HAI (r=0.34).
CONCLUSION: Burnout is most prevalent among non-physicians, daytime workers and experienced workers. Perceptions of working too hard associate with increased HAI in this cohort of VLBW infants, but overall burnout prevalence is not predictive.

CONTEXT: Although a large percentage of children with advanced-stage cancer die at home, remarkably little information is available regarding the experience of general practitioners (GPs) with respect to providing home-based palliative care to children with incurable cancer. OBJECTIVES: The objective of this study was to explore the perspectives of GPs who care for children with advanced-stage cancer in a home-based setting. METHODS: In this cross-sectional study, 144 GPs who provided home-based palliative care to 150 children with incurable cancer from 2001 through 2010 were invited to complete a questionnaire addressing their perspectives regarding: 1) symptom management, 2) collaboration with other health care professionals, 3) the child's death and care after death, and 4) impact of having provided palliative care, scored on distress thermometer (range 0-10). RESULTS: A total of 112 GPs (78%) responded, and 91 GPs completed the questionnaire for 93 patients. The median interval between the child's death and completing the questionnaire was seven years. The most prevalent symptoms reported in the patients were fatigue (67%) and pain (61%). Difficulties with communicating with (14%), coordinating with (11%), collaborating with (11%), and contacting (2%) fellow members of the multidisciplinary treatment team were rare. Hectic (7%) and shocking (5%) situations and panic (2%) around the child's death were rare. GPs reported feelings of sadness (61%) and/or powerlessness (43%) around the time of the patient's death, and they rated their own distress level as relatively high during the terminal phase (median score 6, range 0-9.5). The majority of GPs (94%) reported that they ultimately came to terms with the child's death. CONCLUSION: In general, GPs appear to be satisfied with the quality of home-based palliative care that they provide pediatric patients with incurable cancer. Communication among health care professionals is generally positive and is considered important. Finally, although the death of a pediatric patient has a profound impact on the GP, the majority of GPs eventually come to terms with the child's death.


This study investigates the current position of hospital clowns from the perspective of paediatricians and paediatric residents. A total of 14 attending paediatricians and paediatric residents participated in two focus group sessions. Data were analysed using Atlas.ti 5.0. In general, physicians reported positive experiences regarding the interaction between hospital clowns and paediatric patients on the ward. Physicians were more interested in research on children's perception of hospital clowns than in research on the clinical efficacy of hospital clowning. No direct collaboration between physicians and hospital clowns was reported. However, physicians proposed conditions which may streamline their encounters with hospital clowns such as clear communication prior to hospital clown visits, and the condition that visits do not impede medical interventions. CONCLUSION: Overall, paediatricians and paediatric residents view the positive impact on paediatric patients as the most important aspect of hospital clown visits, rather than the clinical efficacy of hospital clowning. In light of the growing number of hospital clowns worldwide, this article provides recommendations for arranging their encounters with paediatricians and paediatric residents to maintain optimal health care. What is known: * Previous studies show a clinically significant pain- and anxiety-reducing effect of hospital clowning in paediatric patients admitted to hospitals or undergoing (invasive) medical procedures. * In general, paediatricians have positive ideas about hospital clowns, aside from personal prejudices. What is new: * This novel study gives deeper insight into day-to-day interaction between paediatricians and hospital clowns on the ward. * This study provides recommendations for clinical practice to arrange encounters between physicians and hospital clowns during hospital clown visits.


BACKGROUND: Alternative locations for children near end of life (EOL) are lacking in the United States with deaths largely occurring within intensive care units (ICUs). The reflection room (RR) was implemented as a relevant space for providing this care in our hospital. OBJECTIVE: We hypothesized staff would report a positive experience in providing EOL and/or postmortem (PM) care here and would
recommend this to peers. DESIGN: This explorative study summarized room use data and evaluated staff experiences using a voluntary qualitative and quantitative survey. SUBJECTS: The survey was administered to the inpatient interdisciplinary team. RESULTS: From 2011 to 2014, 116 children used the RR, 64% for PM care, and 34% for EOL care. A total of 201 staff responded to the survey. Of them, 90% described the space as a valuable resource to families, 90% reported a preference for using this location versus a hospital unit, and 93% stated they would encourage their peers to do the same. Advantages listed were increased privacy, allowance for more visitors, and a quieter, calmer environment. Challenges included distance from the unit of transfer, managing assignments in two hospital locations, and medication transportation. Overall, there was a measureable decrease in the number of deaths pronounced in the ICU as the number pronounced in the RR increased, illustrating a significant change in practice. CONCLUSION: This study demonstrated an overwhelmingly positive experience in providing EOL and/or PM care to children in the RR and staff would recommend this to peers. This model of care should be a serious consideration for hospitals in the United States.


OBJECTIVE: Compassion fatigue (CF) is distress experienced by caregivers from ongoing contact with patients who are suffering. Burnout (BO) is occupational stress directly related to dissonance between job demands and available resources. Compassion satisfaction (CS) is professional fulfillment experienced through helping others. CF in physicians is not well studied. Neonatologists may be at particular risk for CF by virtue of recurrent exposure to distress in patients and their families. The objectives of this study were to determine the prevalence of CF, BO and CS, and to identify potential predictors for these phenomena in neonatologists. STUDY DESIGN: A modified Compassion Fatigue and Satisfaction Self-Test and a questionnaire of professional details and personal characteristics were distributed electronically to neonatologists nationally. Multivariable logistic and linear regression models for CF, BO and CS as a function of potential predictors were constructed. RESULTS: The survey response rate was 47%. The prevalence of CF, BO and CS was 15.7, 20.8 and 21.9%, respectively. Female gender, emotional depletion, distress from 'a clinical situation', 'co-workers', 'personal health issues' and 'not talking about distressing issues' were each significant determinants of CF. Emotional depletion, distress from the 'physical work environment' and 'co-workers', and 'not talking about distressing issues' were significant determinants of BO. Self-identification as Hispanic; 'not currently feeling distressed'; talking about distressing issues; and utilization of pediatric palliative care services were significant determinants of higher CS. CONCLUSIONS: CF and BO may impact emotional well-being and professional performance of neonatologists. Enhancement of CS is a potential target for intervention.


The Cochrane Library of Systematic Reviews is now only published monthly online (http://www.thecochranelibrary.com ). The methods for searching have changed and are in flux. This report attempted to identify all relevant reviews published in the last 3 months to March 30, 2017. The current version contains 7243 complete reviews and 2544 protocols for reviews in production. In addition, there are citations of 1,036,153 randomized controlled trials (first time passing the million mark) and 15,700 cited papers in the Cochrane Methodology Register. The Health Technology Assessment database contains some 17,000 citations. Six reviews have been identified that have potential relevance for practitioners in pain and palliative medicine. The impact factor of the Cochrane Library stands at 6.1. Readers are encouraged to access the full report for any articles of interest, as only a brief commentary is provided.

BACKGROUND: Due to an absence of communication training, provider responses to patient/family spiritual distress are highly variable. Assessing spiritual and forgiveness concerns are important to ensuring quality holistic care. METHODS: Cross-sectional survey data were collected from providers attending 1 of 2 continuing education courses. The survey measured the frequency and initiation of communication about spirituality and forgiveness with patients/families, the perceived difficulty in communication across topics, and preparation and resources for these discussions. RESULTS: Most participants (n = 124) were nurses followed by social workers with over half of providers having 10 years or more of clinical experience. Participants reported the highest level of difficulty in spiritual communication when talking with family after the death of a patient, followed by conducting a spiritual history with a patient. Facilitating forgiveness communication between parent and adult child, followed by facilitating forgiveness between partners was most difficult for all participants. Social workers reported much lower difficulty than nurses on all items of spiritual and forgiveness communication. CONCLUSION: The majority of participants indicated they were involved in spiritual and forgiveness communication. The most difficult communication included talking with family after death and facilitating forgiveness between patients and families. These findings support the importance of spiritual communication in clinical practice, and the need for clinician training in communicating about spirituality and forgiveness with patients and families.


This paper describes a practice innovation: the addition of formal weekly discussions of patients with prolonged PICU stay to reduce healthcare providers’ moral distress and decrease length of stay for patients with life-threatening illnesses. We evaluated the innovation using a pre/post intervention design measuring provider moral distress and comparing patient outcomes using retrospective historical controls. Physicians and nurses on staff in our pediatric intensive care unit in a quaternary care children’s hospital participated in the evaluation. There were 60 patients in the interventional group and 66 patients in the historical control group. We evaluated the impact of weekly meetings (PEACE rounds) to establish goals of care for patients with longer than 10 days length of stay in the ICU for a year. Moral distress was measured intermittently and reported moral distress thermometer (MDT) scores fluctuated. "Clinical situations" represented the most frequent contributing factor to moral distress. Post intervention, overall moral distress scores, measured on the moral distress scale revised (MDS-R), were lower for respondents in all categories (non-significant), and on three specific items (significant). Patient outcomes before and after PEACE intervention showed a statistically significant decrease in PRISM indexed LOS (4.94 control vs 3.37 PEACE, p = 0.015), a statistically significant increase in both code status changes DNR (11 % control, 28 % PEACE, p = 0.013), and in-hospital death (9 % control, 25 % PEACE, p = 0.015), with no change in patient 30 or 365 day mortality. The addition of a clinical ethicist and senior intensivist to weekly inter-professional team meetings facilitated difficult conversations regarding realistic goals of care. The study demonstrated that the PEACE intervention had a positive impact on some factors that contribute to moral distress and can shorten PICU length of stay for some patients.

https://www.ncbi.nlm.nih.gov/pubmed/27815753


Editor’s Note The journal is delighted to continue a collaboration with the International Association for Hospice and Palliative Care (IAHPC) in publication of book reviews relevant to symptom control in advanced disease. These reviews are adapted from the work of Roger Woodruff, MD, FRACP, FACP, an internationally recognized oncologist and palliative care specialist physician from Australia. Dr.
Woodruff’s reviews appear concurrently or did so previously in the IAHPC Newsletter, which is accessible through the IAHPC Web site: http://hospicecare.com.


OBJECTIVE: To evaluate differences between pediatricians and internists in the practice of and barriers to advance care planning (ACP) for adolescent patients with cancer. STUDY DESIGN: A self-reported questionnaire was administered to assess the practice of ACP, advance directives, and barriers to ACP for adolescent patients with cancer. All 3392 Japanese board-certified hematologists were surveyed, and 600 hematologists (227 pediatricians, 373 internists) who take care of adolescent patients with cancer with decision-making capacity were analyzed. RESULTS: If a patient’s prognosis for survival was <3 months, pediatricians were significantly less likely to discuss ACP with their patients than internists, including discussions regarding the patient’s medical condition (59% vs 70%), the patient’s understanding of his/her medical condition (55% vs 66%), do not attempt resuscitation orders (17% vs 24%), and ventilator treatment if the patient’s condition worsened (19% vs 25%). More than 75% of hematologists (both pediatricians and internists) discussed all ACP topics with patients’ families. Similarly, with regard to advance directives, pediatricians were less likely than internists to discuss cardiopulmonary resuscitation (24% vs 47%) and the use of ventilators (31% vs 51%), vasopressors (24% vs 42%), and antibiotics (21% vs 31%) with their patients. Both pediatricians and internists discussed these issues more often with patients’ families than with patients, especially cardiopulmonary resuscitation (98%) as well as the use of ventilators (98%) and vasopressors (91%). CONCLUSIONS: Pediatricians were less likely than internists to discuss ACP and advance directives with patients, and both pediatricians and internists tended to discuss ACP and advance directives more often with patients’ families.


Trisomy 18 (T18) is a genetic disorder with cardiac lesions in up to 90% of patients. Cardiac surgery is not frequently offered because of the overall poor prognosis, although this has recently been challenged. Our study aimed to explore the practices and attitudes of Canadian pediatric cardiologists managing T18 patients. We administered a survey to pediatric cardiologists attending the Canadian Cardiovascular Congress, Canadian Pediatric Cardiology Association Business Meeting. There were 30 respondents. Most (67%) supported comfort care for affected patients with a heart lesion. None supported palliative surgery for those with complex heart lesions. Of 30 respondents, 16 (53%) counsel families prenatally, and none would present the option of a single ventricle surgical track for complex heart disease. In a hypothetical situation in which their own child was born with T18, 67% would choose comfort care with medical treatment of heart failure, and none would choose palliative surgery. Being a parent was associated with a higher likelihood of choosing termination (14 of 20 vs 6 of 9; P = 0.046) or comfort care (14 of 20 vs 6 of 9; P = 0.036). Qualitative data suggest support for comfort care, while recognizing the need for individualization and shared decision-making, within the context of institution-specific policies. Canadian pediatric cardiologists surveyed support comfort care and medical treatment but not surgical treatment for T18 patients with cardiac lesions. They place primacy on nonmaleficence, yet also recognize the emerging need for individualized shared decision-making in these cases.


BACKGROUND: End-of-life decisions (EoLD) often concern children with profound intellectual and multiple disabilities (PIMD). Yet, little is known about how parents and physicians discuss and make
these decisions. AIMS: The objective of this research was to investigate the experiences of the parents and the involved physician during the end-of-life decision-making (EoLDM) process for children with PIMD. METHODS: In a retrospective, qualitative study, we conducted semi-structured interviews with the physicians and parents of 14 children with PIMD for whom an EoLD was made within the past two years. RESULTS: A long-lasting relationship appeared to facilitate the EoLDM process, although previous negative healthcare encounters could also lead to distrust. Parents and physicians encountered disagreements during the EoLDM process, but these disagreements could also improve the decision-making process. Most parents, as well as most physicians, considered the parents to be the experts on their child. In making an EoLD, both parents and physicians preferred a shared decision-making approach, although they differed in what they actually meant by this concept. CONCLUSION: The EoLDM process for children with PIMD can be improved if physicians are more aware of the specific situation and of the roles and expectations of the parents of children with PIMD.

OBJECTIVE: To describe neonatal intensive care unit (NICU) medical interventions and NICU mortality by birth weight and major anomaly types for infants with trisomy 13 (T13) or 18 (T18). STUDY DESIGN: Retrospective cohort analysis of infants with T13 or T18 from 2005 to 2012 in the Pediatrix Medical Group. We classified infants into three groups by associated anomaly type: neonatal surgical, non-neonatal surgical and minor. Outcomes were NICU medical interventions and mortality. RESULTS: 841 infants were included from 186 NICUs. NICU mortality varied widely by anomaly type and birth weight, from 70% of infants <1500 g with neonatal surgical anomalies to 31% of infants 2500 g with minor anomalies. Infants 1500 g without a neonatal surgical anomaly comprised 66% of infants admitted to the NICU; they had the lowest rates of NICU medical interventions and NICU mortality. CONCLUSIONS: Risk stratification by anomaly type and birth weight may help provide more accurate family counseling for infants with T13 and T18.


AIM: To compare early (<24 hours) echocardiograms (ECHOs) in infants with perinatal hypoxic-ischaemic encephalopathy (HIE) undergoing (i) therapeutic hypothermia (TH), (ii) normothermia and (iii) normal controls. METHODS: This was a single-centre retrospective review of clinical early ECHOs of term infants with moderate or severe HIE and controls (with a normal ECHO <72 hours of age). Right (RVO) and left ventricular output (LVO), RV and LV myocardial performance index (MPI), systolic to diastolic duration ratio (S/D) and eccentricity indices (EI) in systole and diastole were compared using ANOVA. RESULTS: Among infants with HIE (n = 56, 38 in the TH and 18 in normothermia groups), 14 (25%) infants died and 42 survived. Significantly elevated biventricular MPI, lower RVO and LVO and pulmonary hypertension (abnormal EI, higher RV S/D and bidirectional or right-to-left ductal shunt) were found in groups with HIE, compared to controls (n = 35). LV MPI was lower in HIE-TH, compared to the HIE-normothermia group. Infants with HIE who died (n = 14) had a significantly lower Eld [0.77 (0.09) vs. 0.83 (0.08), p = 0.021] compared to survivors (n = 42). CONCLUSION: Infants with perinatal HIE have ventricular dysfunction; those who died had significantly lower Eld than survivors; this association needs to be further validated.


AIM: This study determined whether there was a difference in the conclusions reached by neonatologists in morbidity and mortality conferences based on their level of involvement in a case. METHODS: All neonatal deaths occurring between August 2014 and September 2015 at the neonatal intensive care unit of Sainte-Justine Hospital, Montreal, Quebec, Canada, were reviewed by internal physicians involved in the case and external physicians who were not. The reviewers were asked to identify positive and negative clinical practice items and provide written recommendations. These were classified into eight categories and compared for each case. RESULTS: During the study, 55 patients died leading to 110 reviews and a total of 590 positive and negative items. Most items were in the communication (25.2%), ethical decision-making (16.7%) and clinical management (14.8%) categories. Both the internal and external reviewers were in agreement 48.5% of the time for positive items and 44.8% for negative items. There were 242 written recommendations, which differed significantly among the internal and external
reviewers. CONCLUSION: Reviews of neonatal deaths by two independent reviewers, internal physicians and external physicians, led to different positive and negative practice items and recommendations. This could allow for a richer discussion and improve recommendations for patient care. 


CONTEXT: Specialized pediatric palliative home care (SPPHC) is the main pediatric palliative care structure in Germany. Detailed data on patient characteristics and care are sparse. Describing this population in terms of diagnoses and care needs is essential for further development of palliative care services for these patients. OBJECTIVES: We asked whether the population at our center 1) was representative compared with national mortality statistics; 2) showed differences in the clinical course among the four diagnostic categories established by the Association for Children with Terminal Conditions/Royal College of Paediatrics and Child Health; and 3) was different to published populations in pediatric palliative care regarding diagnoses, care, and place of death. METHODS: Retrospective single center chart analysis of 212 consecutive patients on SPPHC (2009-2015). RESULTS: Main International Statistical Classification of Diseases and Related Health Problems, 10th Revision groups were nervous system, congenital abnormalities, neoplasia, and metabolic disease, reflecting the mortality statistics for patients one to 20 years. Thirty-six percent of patients were assigned to ACT-3, 34% to ACT-4, 26% to ACT-1, and 4% to ACT-2. ACT-1 patients mostly needed high-intensity care for short durations, ACT-4 patients showed long survival times with mostly intermittent care. Seventy-five percent of patients showed nervous system involvement. Eighty-four percent died at home, 12% in hospital, and 4% in a hospice, with 96% dying at their preferred place. CONCLUSION: Our data on SPPHC show 1) significant differences between Association for Children with Terminal Conditions/Royal College of Paediatrics and Child Health groups in terms of care needs and survival; 2) a high prevalence of children with neurological problems; and 3) a large majority of children dying at home. 


While pediatric survival rates have increased over the past 40 years, it has been well established that cancer and its treatment significantly impact children and their families. For the majority of families, a child’s cancer diagnosis and treatment is the most difficult life experience they will face. While most families adjust to this significant stressor, there is no doubt that coping with the treatment process is an extremely difficult experience with multiple psychosocial consequences (Liptak, Zelter, &amp; Recklitis, 2015). This paper highlights the emotional and psychological impacts of cancer and its treatment on children and their families at each developmental stage and highlights common issues across the cancer treatment continuum. Combined knowledge of developmental and treatment stage complexities is essential to inform providers of how best to care for these children and families. 


Childhood interstitial lung disease (cILD) comprises a wide heterogeneous group of rare parenchymal lung disorders associated with substantial morbidity and mortality. Pulmonary hypertension is a common comorbidity in adults with interstitial lung disease (ILD) and associated with poor survival. We aimed to systematically review the literature regarding the occurrence of pulmonary hypertension (PH) in cILD, its effect on prognosis and healthcare use, and its treatment in clinical practice. Searches of PubMed and EMBASE databases (up to February 2016), and American Thoracic Society conference abstracts (2009-2015) were conducted using relevant keywords. References from selected articles and review papers were scanned to identify further relevant articles. A total of 20 articles were included; estimates of PH in
chILD ranged from 1% to 64% with estimates among specific chILD entities ranging from 0% to 43%. Comparisons between studies were limited by differences in the study populations, including the size, age range, and heterogeneous composition of the ILD case series in terms of the nature and severity of the clinical entities, and also the methods used to diagnose PH. Three studies found that among patients with chILD, those with PH had a significantly higher risk (up to sevenfold) of death compared with those without PH. Information on the treatment of pulmonary hypertension in chILD or the effect of PH on healthcare use was not available. Data on the use and effectiveness of treatments for pulmonary hypertension in chILD are required to address this area of unmet need. Pediatr Pulmonol. 2017;52:689-698. (c) 2016 Wiley Periodicals, Inc.


INTRODUCTION: Despite improvements of neonatal intensive care, mortality among patients born with congenital diaphragmatic hernia (CDH), remains high, and there is a significant late mortality in this cohort. OBJECTIVE: The aim of this study was to evaluate the causes of death among 251 consecutive CDH patients treated at our institution during the last 26 years period. METHODS: Retrospective review of all causes of death between 1990 and 2015 of the CDH cohort prospectively collected in a database. RESULTS: Of the 251 CDH patients treated in our department since 1990, 49 were not alive by the end of 2015. Thirty-six patients (14%) died before discharge, and 13 (5%) after the first care event. The mean age at death was 262 days (+/- 653 days, median 34 days). Eighty-six% (42 cases) of the fatalities occurred during the first year of life, more than half of the patients died before 1 month of age and only 13% after the age of 1 year (7 patients) (late mortality). The causes of early mortality (before 1 year of age) were mainly cardio-respiratory, whereas GI complications occurred in the late mortality group. CONCLUSION: The most common cause of death among CDH patients is respiratory insufficiency and associated pulmonary hypertension, and most of the fatalities occur before 1 year of age. Among older patients, gastrointestinal morbidity as cause of death is highly represented. LEVEL OF EVIDENCE: II.


CONTEXT: The need for children’s palliative care (CPC) globally is unknown. To understand the scope of the need and to advocate to meet it, more accurate estimates are needed. OBJECTIVES: The objective of this study was to create an accurate global estimate of the worldwide need for CPC based on a representative sample of countries from all regions of the world and all World Bank income groups. METHODS: This work builds on previously published methods developed by the International Children’s Palliative Care Network, United Nations Children’s Fund, and World Health Organization and tested in three African countries. The study used a cross-sectional design with quantitative data obtained from primary and secondary data sources. Estimation of the need used prevalence data from the Institute for Health Metrics and Evaluation, mortality data from the World Health Organization for the specific diseases known to require CPC, and Joint United Nations Programme on HIV/AIDS (UNAIDS) data on HIV prevalence. Representative data were analyzed for 23 countries representing 59.5% of the world’s population. RESULTS: The findings show estimated need for CPC ranged from almost 120 per 10,000 children in Zimbabwe to slightly more than 20 per 10,000 in the United Kingdom. Overall, among the over 21 million with conditions that will benefit annually from a palliative care approach, more than eight million need specialized CPC worldwide. CONCLUSION: The estimation of need for CPC is a critical step in meeting the needs of children with life-threatening conditions and provides a sound platform to advocate for closure of the unacceptably wide gaps in coverage.

BACKGROUND: Melanoma is a rare neoplasm in the pediatric population. Recent publications suggest a possible increase in incidence over the past few decades. The purpose of this study was to analyze trends in pediatric patients diagnosed with malignant melanoma in British Columbia (BC) in the past 35 years. METHODS: A retrospective review was performed. All patients in BC diagnosed with melanoma before 18 years of age from 1979 to 2014 were included. Patient demographics, melanoma description, treatment details, and survival data were collected. RESULTS: Seventy-eight subjects were identified for the study. Patients were equally distributed by sex. Sixty-one (78%) of the subjects were diagnosed in the postpubertal age (≥12 years old). The most common sites of occurrence were the extremities (n = 33) and the trunk (n = 27), with the location on the trunk showing the highest mortality rate (22%). All patients were surgically treated and some had additional chemotherapy (12) and/or radiotherapy (12). Fatal outcome was recorded in 12 of the 78 subjects, 10 of whom had postpubertal diagnosis. The average time from date of diagnosis to date of death was 9.3 years. CONCLUSIONS: The incidence of melanoma in the pediatric population remains exceedingly rare: less than 2.5 per million children younger than 18 years. The diagnosis is rarely made before puberty; the incidence is equal in males and females and has not changed over a 35-year time period in BC. Our study shows 85% survival with the majority of patients having had surgical excision only.


Death in children with epilepsy is profoundly disturbing, with lasting effects on the family, community, and health care providers. The overall risk of death for children with epilepsy is about ten times that of the general population. However, the risk of premature death for children without associated neurological comorbidities is similar to that of the general population, and most deaths are related to the cause of the epilepsy or associated neurological disability, not seizures. The most common cause of seizure-related death in children with epilepsy is sudden unexpected death in epilepsy (SUDEP). SUDEP is relatively uncommon in childhood, but the risk increases if epilepsy persists into adulthood. Although the direct cause of SUDEP remains unknown, most often death follows a generalized convulsive seizure and the risk of SUDEP is strongly related to drug-resistant epilepsy and frequent generalized tonic-clonic seizures. The most effective SUDEP prevention strategy is to reduce the frequency of seizures, although a number of seizure detection devices are under development and in the future may prove to be useful for seizure detection for those at particularly high risk. There are distinct benefits for health care professionals to discuss mortality with the family soon after the diagnosis of epilepsy. An individual approach is appropriate. When a child with epilepsy dies, particularly if the death was unexpected, family grief may be profound. Physicians and other health care professionals have a critical role in supporting families that lose a child to epilepsy. This review will provide health care providers with information needed to discuss the risk of death in children with epilepsy and support families following a loss.


Krabbe disease (KD) is a rare neurodegenerative disorder caused by mutations in the gene encoding the galactocerebrosidase enzyme. The early- and late-infantile subtypes, which are the most common forms of the disease, are rapidly progressive and lead to early death, whereas the later-onset types are clinically heterogeneous. The only disease-modifying treatment currently available is hematopoietic stem cell transplantation, which is effective only when performed early in the course of the disease. Because most patients with KD are diagnosed too late for treatment, primary care physicians are faced with the challenge of caring for a child with severe neurologic impairment. This Review describes presenting symptoms, diagnosis, and disease manifestations of KD and provides basic guidelines for its management. Symptomatic treatment and supportive care that address the unique requirements of
these patients can greatly improve the quality of life of patients and their families. (c) 2016 Wiley Periodicals, Inc. 


Spinal muscular atrophy (SMA) is a hereditary neurodegenerative disease with severity ranging from progressive infantile paralysis and premature death (type I) to limited motor neuron loss and normal life expectancy (type IV). Without disease-modifying therapies, the impact is profound for patients and their families. Improved understanding of the molecular basis of SMA, disease pathogenesis, natural history, and recognition of the impact of standardized care on outcomes has yielded progress toward the development of novel therapeutic strategies and are summarized. Therapeutic strategies in the pipeline are appraised, ranging from SMN1 gene replacement to modulation of SMN2 encoded transcripts, to neuroprotection, to an expanding repertoire of peripheral targets, including muscle. With the advent of preliminary trial data, it can be reasonably anticipated that the SMA treatment landscape will transform significantly. Advancement in presymptomatic diagnosis and screening programs will be critical, with pilot newborn screening studies underway to facilitate preclinical diagnosis. The development of disease-modifying therapies will necessitate monitoring programs to determine the long-term impact, careful evaluation of combined treatments, and further acceleration of improvements in supportive care. In advance of upcoming clinical trial results, we consider the challenges and controversies related to the implementation of novel therapies for all patients and set the scene as the field prepares to enter an era of novel therapies. Ann Neurol 2017;81:355-368. 


Wilms tumour (WT) is the commonest primary malignant renal tumour of childhood. Acquired von Willebrand syndrome (avWS) is a well-described paraneoplastic phenomenon, but it is uncommon and may not be detected until clinically significant bleeding is encountered during interventional procedures. Previous studies on small cohorts of patients have determined an incidence of between 4 and 8%. We have performed a retrospective study on cases of WT presenting over an 11.5-year period to a paediatric haematology/oncology unit in a tertiary referral centre to review the incidence of avWS, bleeding phenotype, management, and response to treatment of the primary pathology. 


Purpose Despite advances in childhood cancer care, some patients die soon after diagnosis. This population is not well described and may be under-reported. Better understanding of risk factors for early death and scope of the problem could lead to prevention of these occurrences and thus better survival rates in childhood cancer. Methods We retrieved data from SEER 13 registries on 36,337 patients age 0 to 19 years diagnosed with cancer between 1992 and 2011. Early death was defined as death within 1 month of diagnosis. Socioeconomic status data for each individual's county of residence were derived from Census 2000. Crude and adjusted odds ratios and corresponding 95% CIs were estimated for the association between early death and demographic, clinical, and socioeconomic factors. Results Percentage of early death in the period was 1.5% (n = 555). Children with acute myeloid leukemia, infant acute lymphoblastic leukemia, hepatoblastoma, and malignant brain tumors had the highest risk of early death. On multivariable analysis, an age younger than 1 year was a strong predictor of early death in all disease groups examined. Black race and Hispanic ethnicity were both risk factors for
early death in multiple disease groups. Residence in counties with lower than median average income
was associated with a higher risk of early death in hematologic malignancies. Percentages of early death
decreased significantly over time, especially in hematologic malignancies. Conclusion Risk factors for
early death in childhood cancer include an age younger than 1 year, specific diagnoses, minority race
and ethnicity, and disadvantaged socioeconomic status. The population-based disease-specific
percentages of early death were uniformly higher than those reported in cooperative clinical trials,
suggesting that early death is under-reported in the medical literature. Initiatives to identify those at risk
and develop preventive interventions should be prioritized.

country: telling it like it is." Trop Doct: 49475517704363.

Neuroblastoma is uncommon in Africa, but when seen usually presents as high-risk disease with a poor
prognosis. This aggressive biology of the tumour is frequently augmented by delayed presentation.
Current treatment depends upon technologies and skills that are scarce in developing countries and the
cost involved is generally beyond the means of healthcare providers who are faced with a myriad more
pressing healthcare issues. The presentation, treatment and outcome of 45 African children with
neuroblastoma are described. Due to a lack of resources precise risk stratification was impossible but
visceral or bone metastases were present in 73% of patients at diagnosis. In 91% the primary tumour
was intra-abdominal. Three children (7%) were paraplegic on admission. A localised tumour was seen in
one child (2%). Fifteen children (33%) underwent a surgical procedure, with intent to cure in five among
whom resection was incomplete in three. For all other children, treatment was palliative using
chemotherapy with judicious use of radiotherapy. Thirteen children (29%) survived longer than six
months. Overall survival at three years was 4%.

Houttekier and J. Cohen (2017). "Place of death of children with complex chronic conditions:

Cross-national understanding of place of death is crucial for health service systems for their provision of
efficient and equal access to paediatric palliative care. The objectives of this population-level study were
to examine where children with complex chronic conditions (CCC) die and to investigate associations
between places of death and sex, cause of death and country. The study used death certificate data of
all deceased 1- to 17-year-old children (n = 40,624) who died in 2008, in 11 European and non-
European countries. Multivariable logistic regression was performed to determine associations between
place of death and other factors. Between 24.4 and 75.3% of all children 1-17 years in the countries
died of CCC. Of these, between 6.7 and 42.4% died at home. In Belgium and the USA, all deaths
caused by CCC other than malignancies were less likely to occur at home, whereas in Mexico and South
Korea, deaths caused by neuromuscular diseases were more likely to occur at home than malignancies.
In Mexico (OR = 0.91, 95% CI: 0.83-1.00) and Sweden (OR = 0.35, 95% CI: 0.15-0.83), girls had a
significantly lower chance of dying at home than boys. CONCLUSION: This study shows large cross-
national variations in place of death. These variations may relate to health system-related infrastructures
and policies, and differences in cultural values related to place of death, although this needs further
investigation. The patterns found in this study can inform the development of paediatric palliative care
programs internationally. What is known: * There is a scarcity of population-level studies investigating
where children with CCC die in different countries. * Cross-national understanding of place of death
provides information to health care systems for providing efficient and equal access to paediatric
palliative care. What is new: * There are large cross-national variations in the place of death of children
with CCC, with few deaths occurring at home in some countries whereas hospital deaths are generally
most common. * In general, deaths caused by neuromuscular diseases and malignancies occur at home
more often than other CCC.
OBJECTIVE: To determine the incidence rates of sudden unexpected death in epilepsy (SUDEP) in different epilepsy populations and address the question of whether risk factors for SUDEP have been identified. METHODS: Systematic review of evidence; modified Grading Recommendations Assessment, Development and Evaluation process for developing conclusions; recommendations developed by consensus. RESULTS: Findings for incidence rates based on 12 Class I studies include the following: SUDEP risk in children with epilepsy (aged 0-17 years) is 0.22/1,000 patient-years (95% CI 0.16-0.31) (high confidence in evidence). SUDEP risk increases in adults to 1.2/1,000 patient-years (95% CI 0.64-2.32) (low confidence in evidence). The major risk factor for SUDEP is the occurrence of generalized tonic-clonic seizures (GTCS); the SUDEP risk increases in association with increasing frequency of GTCS occurrence (high confidence in evidence). RECOMMENDATIONS: Level B: Clinicians caring for young children with epilepsy should inform parents/guardians that in 1 year, SUDEP typically affects 1 in 4,500 children; therefore, 4,499 of 4,500 children will not be affected. Clinicians should inform adult patients with epilepsy that SUDEP typically affects 1 in 1,000 adults with epilepsy per year; therefore, annually 999 of 1,000 adults will not be affected. For persons with epilepsy who continue to experience GTCS, clinicians should continue to actively manage epilepsy therapies to reduce seizures and SUDEP risk while incorporating patient preferences and weighing the risks and benefits of any new approach. Clinicians should inform persons with epilepsy that seizure freedom, particularly freedom from GTCS, is strongly associated with decreased SUDEP risk.


OBJECTIVE: To determine the clinical stage (stable, unstable, deteriorating or dying) for children and young people (CYP) aged 0-25 years in Scotland with life-limiting conditions (LLCs). DESIGN: National cohort of CYP with LLCs using linked routinely collected healthcare data. SETTING: Scotland. PATIENTS: 20 436 CYP identified as having LLCs and resident in Scotland between 1 April 2009 and 31 March 2014. MAIN OUTCOME: Clinical stage based on emergency inpatient and intensive care unit admissions and date of death. RESULTS: Over 2200 CYP with LLCs in Scotland were unstable, deteriorating or dying in each year. Compared with 1-year-olds to 5-year-olds, children under 1 year of age had the highest risk of instability (OR 6.4, 95% CI 5.7 to 7.1); all older age groups had lower risk. Girls were more likely to be unstable than boys (OR 1.15, 95% CI 1.06 to 1.24). CYP of South Asian (OR 1.61, 95% CI 1.28 to 2.01), Black (OR 1.58, 95% CI 1.04 to 2.41) and Other (OR 1.33, 95% CI 1.02 to 1.74) ethnicity were more likely to experience instability than White CYP. Deprivation was not a significant predictor of instability. Compared with congenital abnormalities, CYP with most other primary diagnoses had a higher risk of instability; only CYP with a primary perinatal diagnosis had significantly lower risk (OR 0.23, 95% CI 0.19 to 0.29). CONCLUSIONS: The large number of CYP with LLCs who are unstable, deteriorating or dying may benefit from input from specialist paediatric palliative care. The age group under 1 and CYP of South Asian, Black and Other ethnicities should be priority groups.

of methadone-induced prolongation of the QTc interval in children and young adults is unknown. The purpose of the study was to determine the frequency of QTc prolongation among pediatric and young adult patients with cancer pain on methadone treatment. METHODS: We retrospectively reviewed data for all patients on methadone during the study period. Qualifying patient data were reviewed to determine whether these patients had an electrocardiogram (ECG) while on methadone. The QTc values for analysis were manually calculated using the standard formula described by Bazett. RESULTS: Twenty-five patients were identified that met eligibility criteria. The median QTc decreased from baseline after initiation of methadone. QTc prolongation occurred in four of 25 (16%) patients and only one patient had a QTc greater than 500 msec. This patient had 17 normal QTc intervals on methadone prior to the prolongation. After resolution of electrolyte abnormalities, six subsequent ECGs on methadone had a normal QTc interval. CONCLUSIONS: Prolongation of the QTc interval is infrequent. The only observed case was transient during multiple comorbid conditions. A prospective study is justified to better understand what role methadone plays as one of many risk factors for prolongation of the QTc interval in children and young adults.


BACKGROUND: Fetal specialists support standardizing the practice of offering women palliative care for life limiting fetal diagnoses. However, there is little data available regarding what fetal specialists do in practice. Since 2003, our center has kept a database of all women referred for fetal complications. METHODS: Retrospective electronic chart review of pregnant women between 2006 and 2012 using UCSD’s Fetal Care and Genetics Center referral database. Objectives were to determine: (I) how many high risk pregnancies referred to the University of California San Diego Medical Center (UCSD) over a 6-year period have potentially life limiting fetal diagnoses; (II) pregnancy outcome; and (III) referral rate to perinatal palliative care. RESULTS: Between July 2006 and July 2012, 1,144 women were referred to UCSD’s Fetal Care and Genetics Center, a tertiary care center. Of that cohort, 332 women (29%) were diagnosed prenatally with a potentially life limiting fetal diagnosis. Most women were Hispanic or Latino, married, and had previous children. The median gestation at confirmed diagnosis was 19 weeks. Trisomy 13, Trisomy 18, and anencephaly comprised 21% of cases. The pregnancy outcome was determined in 95% cases: 56% therapeutic abortion, 16% intrauterine fetal demise, and 23% live birth. Only 11% of cases were referred to perinatal palliative care. CONCLUSIONS: The vast majority of women with potentially life limiting fetal diagnoses are not referred to perinatal palliative care. Evaluation of how to integrate palliative care into high-risk obstetrics is needed.


INTRODUCTION: In France, 26 regional pediatric palliative care teams (ERRSPP) were created between 2008 and 2012. We conducted the first prospective French study to describe the main specifications of the initial contact with an ERRSPP and to analyze the responses given. DESIGN AND METHODS: All the requests for interventions on the part of the ERRSPP were collected between September 2013 and September 2014. We prospectively completed a questionnaire on the patient’s clinical and demographic data (age, sex, disease), details regarding the request (type of applicant, unit’s specialty, request pattern), and the answers provided (interval between diagnosis and request, duration of care by ERRSPP, death, changes compared to the initial request). The diseases were classified within one of the six groups of palliative pediatric care diseases, based on the standards of the Canadian palliative care association. RESULTS: We gathered 67 requests, 61 relating to patients. The median age at the request was 49.8 months (range: 2.3-145). The original pattern was multiple: multidisciplinary decision-making (42 %), coordination of care (34 %), symptom management (21 %), logistic support for home care (19 %), education (9 %) and case discussion (6 %). Requests concerning multidisciplinary decision-making were predominant within the neonatal period (61 %); coordination of care was significant for children and
adolescents (78% after 4 years of age). The study of the median time from diagnosis to request compared to the groups of diseases revealed a short time in group 5 (neonatology: 0.36 months) and a long time in group 4 (irreversible and nonscalable diseases: 54.6 months) (P<0.001). At the end of the study, the follow-up of 50.8% of the patients by ERRSPP was still going on (median duration of care by the ERRSPP of Languedoc-Roussillon region [ERRSPP-LR], 3.4 months [range: 0.2-5.5]). No request was formulated by a general practitioner. CONCLUSION: This study shows the heterogeneity of the initial contact made with an ERRSPP, confirming its different assignments and the need for a multidisciplinary team. The ERRSPP’s answer was expanded in half of the cases, attesting to the changing needs over time.


BACKGROUND: Understanding early-life risk factors for childhood death in cystic fibrosis (CF) is important for clinical care, including the identification of effective interventions. METHODS: Data from the Epidemiologic Study of Cystic Fibrosis (ESCF) collected 1994-2005 were linked with the Cystic Fibrosis Foundation Patient Registry (CFFPR) demographic and mortality data from 2013. Inclusion criteria were >/=1 visit annually at age 3-5 years and >/=1 FEV1 measurement at age 6-8 years. Demographic data, nutritional parameters, pulmonary signs and symptoms, microbiology, and FEV1 were evaluated as risk factors for death before age 18 years. Multivariable Cox proportional hazards regression was used to model the simultaneous effects of risk factors associated with death before age 18 years. RESULTS: Among 5365 patients enrolled in ESCF who met inclusion criteria, 3880 (72%) were linked to the CFFPR. Among these, 191 (5.7%) died before age 18 years; median age at death was 13.4 +/- 3.1 years. Multivariable regression showed clubbing, crackles, female sex, unknown CFTR genotype, minority race or ethnicity, Medicaid insurance (a proxy of low socioeconomic status), Pseudomonas aeruginosa on 2 or more cultures, and weight-for-age <50th percentile were significant risk factors for death regardless of inclusion of FEV1 at age 6-8 years in the model. CONCLUSION: We identified multiple risk factors for childhood death of patients with CF, all of which remained important after incorporating FEV1 at age 6-8 years. Among the factors identified were the presence of clubbing or crackles at age 3-5 years, signs which are not routinely collected in registries.


INTRODUCTION: Home ventilation (HV) for children is growing rapidly worldwide. The aim was to describe (1) the sociodemographic characteristics of children on HV and (2) the indications for, means and outcome of initiating HV in children from a developing country. METHODOLOGY: This retrospective study included patients sent home on noninvasive or invasive ventilation, over 13 years, by the pediatric respiratory unit in a single center. Children who declined treatment were excluded. RESULTS: Seventy children were initiated on HV: 85.7% on noninvasive ventilation, 14.3% on invasive ventilation. There was about a threefold increase from 2001-2008 (n = 18) to 2009-2014 (n = 52). Median (range) age of initiating HV was 11 (1-169) months and 73% of children were <2 years old. Common indications for HV were respiratory (57.2%), chest/spine anomalies (11.4%), and neuromuscular (10.0%). Fifty-two percent came off their devices with a median (interquartile range) usage duration of 12 (4.8, 21.6) months. Ten children (14.3%) died with one avoidable death. Children with neuromuscular disease were less likely to come off their ventilator (0.0%) compared to children with respiratory disease (62.1%). Forty-one percent of parents bought their equipment, whereas 58.6% borrowed their equipment from the medical social work department and other sources. CONCLUSION: HV in a resource-limited country is possible. Children with respiratory disease made up a significant proportion of those requiring HV and were more
Lennox-Gastaut syndrome is a severe, childhood-onset electroclinical syndrome comprised of multiple seizure types, intellectual and behavioral disturbances and characteristic findings on electroencephalogram of slow spike and wave complexes and paroxysmal fast frequency activity. Profound morbidity often accompanies a common and severe seizure type, the drop attack. Seizures often remain refractory, or initial treatment efficacy fades. Few individuals are seizure free despite the development of multiple generations of antiseizure medications over decades and high-level evidence on several choices. Approved medications such as lamotrigine, topiramate, rufinamide, felbamate and clobazam have demonstrated efficacy in reducing seizure burden. Cannabidiol has emerged as a promising investigational therapy with vast social interest yet lacks a standard, approved formulation. Palliative surgical procedures, such as vagal nerve stimulation and corpus callosotomy may provide reduction in total seizures and drop attacks. Emerging evidence suggests that complete callosotomy provides greater improvement in seizures without additional side effects. Etiologies such as dysplasia or hypothalamic hamartoma may be amenable for focal resection and thus offer potential to reverse this devastating epileptic encephalopathy.


BACKGROUND: Little is known about cystic fibrosis patients, who are not considered to be terminally ill, and who die after voluntary cessation of treatment. AIM: This study was undertaken to provide an international snapshot of this issue. DESIGN: An online survey was distributed across three continents. SETTING: Distribution to the medical directors of the cystic fibrosis centres affiliated with the US Cystic Fibrosis Foundation, Cystic Fibrosis Australia (inclusion of New Zealand) and to every clinician member of the European Cystic Fibrosis Society. RESULTS: More than 200 cystic fibrosis patients not considered to be terminally ill and, who voluntarily ceased treatment, were reported by the clinicians surveyed. Detailed data were reported in 102 patients (4 children, 25 adolescents and 73 adults). Only one child, six adolescents and one adult were judged by clinicians not to be competent to make the decision to stop treatment. Time-consuming and low immediate-impact therapies, such as respiratory physiotherapy, were most frequently discontinued. Resignation was the main reported reason for discontinuing treatment, followed by reactive depression and lack of familial support. A total of 69% of the patients received palliative care and 72% died in the 6 months following cessation of treatment. CONCLUSION: Death of cystic fibrosis patients, not considered to be terminally ill, is reported in Europe, the United States and Australia due to voluntary cessation of treatment.


Juvenile Huntington’s disease (JHD) is a neurodegenerative disease with onset prior to the age of 21. While it accounts for a relatively small proportion of Huntington’s disease (HD) diagnoses, its impact is significant on the quality of life for those affected. Clinicians may be unaware that HD can present in childhood and adolescence, delaying diagnosis. HD develops due to an expanded CAG repeat in the
huntington gene. Rigidity, dystonia, and seizures are more common in JHD. Cognitive changes such as executive function impairments and decline in school performance are common. The burden of psychiatric symptoms is considerable and includes depression, anxiety, impulsivity, and aggression. While novel approaches to treatment interventions are investigated, current care is limited to targeting symptoms rather than disease modification. Prompt diagnosis and symptomatic treatment can maximize quality of life for these patients.


INTRODUCTION: EMMS International and Emmanuel Hospital Association (EHA) implemented a pilot project, poverty reduction in India through palliative care (PRIPCare). A total of 129 interviews with patients and family enrolled in palliative care at three EHA hospitals (in Fatehpur, Lalitpur and Utraula) and staff discussions established that 66% of palliative care patients had lost livelihoods due to illness, 26% of patients’ families had members who had lost livelihoods due to the illness, 98% of enrolled households had debts, 59% had loans for which they had sold assets, 69% of households took out debt after their family member fell ill, many patients do not know about government benefits and lack necessary documents, many village headmen require bribes to give people access to benefits, and many bereaved women and children lose everything. Palliative care enabled 85% of patients and families to spend less on medicines, 31% of patients received free medicines, all patients reduced use of out-patient departments (OPDs), 20% reduced use of inpatient departments (IPDs), and therefore spent less on travel, 8% of patients had started earning again due to improved health, members of 10% of families started earning again, and one hospital educated 171 village headmen and increased by 5% the number of patients and their families receiving government benefits. If only 0.7% of needy adults are receiving palliative care, these benefits could be delivered to 143 times more families, targeted effectively at poverty reduction. Palliative care has great scope to reduce that most desperate poverty in India caused by chronic illness. CONTEXT: This article concerns a study by the UK NGO EMMS International and Indian NGO EHA, to assess whether palliative care reduces household poverty. AIMS: EHA staff had noticed that many patients spend a lot on ineffective treatment before joining palliative care, many families do not know their entitlement to government healthcare subsidies or government pensions, and many bereaved widows and children are disinherited. Convinced that palliative care can address these, EMMS and EHA implemented PRIPCare - a pilot project. SETTINGS AND DESIGN: EHA began training staff for rural palliative care in north India in 2009, and started its first palliative care service at Harriet Benson Memorial Hospital, Lalitpur, Uttar Pradesh, in 2010, with home-based care backed by hospital out- and in-patient care. With EMMS support since 2012, EHA's palliative care service functions in eight hospitals in six states and Delhi. SUBJECTS AND METHODS: EMMS International provided the concept, commissioned the study and reviewed the report. EHA hired and guided a consultant, who piloted a questionnaire in EHA's Delhi Shalom Centre, and conducted 129 in-depth, one-to-one interviews in July and August 2015 with patients or close family members enrolled in the palliative care of three EHA rural hospitals, in Fatehpur, Lalitpur and Utraula. This represents 83% of patients in these hospitals, which in July 2015 was 79 patients in Lalitpur, 39 in Utraula, and 38 in Fatehpur. The questionnaire concerned illness, cost of treatment, use of government benefits, and family economic status. The consultant held focus group discussions with palliative care staff in these three hospitals. STATISTICAL ANALYSIS: An intern in EHA’s Shalom Centre in Delhi entered data into Excel. The consultant analysed it using Excel. RESULTS: Poverty of palliative care patients 18% of households enrolled for palliative care earn <Rs 5000/month63% of households, the highest wage earner earns <Rs 5000/month66% of palliative care patients had lost their livelihoods due to illness26% of patients’ families had members who had lost livelihoods due to the illnessBefore palliative care, 80% of households paid for medicine, treatment, laboratory tests and travel to healthcare98% of enrolled households have debts; 59% had sold assets to gain 0-interest loans69% of households took out their debt after their family member fell ill11% of enrolled households receive government benefits49% of households have food cards or below poverty line cardsMany patients do not know their rights to government benefitsMany patients lack documents to enroll for government benefits Many village headmen demand bribes to list people as eligible for benefitsPatients do not plan inheritance; many bereaved women and children lose everything. Poverty
reduction through palliative care 85% of patients and families spent less monthly on medicine and travel after joining palliative care than before, due to symptom management, cheaper medicine, and home-based care. 31% of patients received free medicines on the palliative care programme. All patients reduced the use of OPDs after joining palliative care. 20% reduced use of IPDs. Both contributed to lower travel expenditure. 8% of palliative care patients started earning again due to improved health. Members of 10% of families started work again through palliative care respite. Staff tell families of benefits to which they are entitled and how to get them. One hospital palliative care team educated 171 Pradhans and increased by 5% the proportion of palliative care patients and families who receive government benefits. Early diagnosis plus immediate enrollment on palliative care contributes to greater household poverty prevention and reduction, and greater dignity. Palliative care’s awareness-raising has increased the number of patients enrolling on palliative care. Expanded services could enroll people earlier in their illness, since 59% of patients were diagnosed over 2 years ago, but only 19% of patients had been on the palliative care programme for 2 years. Reduced use of OPD and IPD free up regular hospital services for others. In India, approximately 645,441 children on any 1 day need palliative care, but only 0.7% of them receive it (ICPCN, EMMS, 2015). If only 0.7% of needy adults are receiving palliative care, then the benefits above could be delivered to 143 times more families, if targeted effectively at poverty reduction. CONCLUSIONS: Holistic palliative care can reduce the desperate poverty driven by life-limiting illness, and can do so systematically, on a large-scale, in-depth, especially if started early in the illness. Home-based care also frees up hospitals to serve more patients with treatable conditions.


OBJECTIVE: To identify all cases of sudden unexpected death in epilepsy (SUDEP) among people in Sweden during 1 year and to determine the SUDEP incidence in relation to age, sex, and psychiatric comorbidity. METHODS: We included all individuals with a hospital-based ambulatory care or hospital discharge diagnosis of epilepsy in the Swedish National Patient Registry during 1998-2005 who were alive on January 1, 2008. Deaths during 2008 were identified by linkage to the National Cause of Death Registry. Death certificates, medical charts, and police and autopsy reports were extensively reviewed to identify SUDEP cases. RESULTS: Of 57,775 epilepsy patients alive on January 1, 2008, 1,890 died (3.3%) during 2008. Of these, 99 met the Annegers SUDEP criteria (49 definite, 19 probable, and 31 possible). SUDEP accounted for 5.2% of all deaths and 36% of deaths in the 0-15 years age group. The incidence of definite/probable SUDEP was 1.20/1,000 person-years, and higher in men (1.41) than in women (0.96). All SUDEP cases <16 years were in boys. SUDEP incidence at ages <16, 16-50, and >50 years was 1.11, 1.13, and 1.29, respectively, per 1,000 person-years. The incidence was 5-fold increased among children with psychiatric comorbidities compared to those without. Epilepsy was mentioned on the death certificate in only 62 of the 99 (63%) SUDEP cases. CONCLUSIONS: Methods relying on death certificates underestimate SUDEP incidence. SUDEP risk has been underestimated especially in boys and in older people regardless of sex. Patients with psychiatric comorbidities, women in particular, are at increased SUDEP risk.


BACKGROUND: More children are living with serious illness. However, survival and complexity of illnesses have not been described. OBJECTIVE: To describe types of illnesses, timing of referral, and time to death following referral to palliative care; to examine the associations between demographics and clinical characteristics and patient survival; and to examine whether average daily pain decreases after referral. DESIGN: Retrospective chart review of all children ages 2-16 years referred to palliative care at one large children’s hospital during the five-year study period from January 1, 2009, through December 31, 2013. MEASUREMENTS: The primary outcome was patient survival and the main independent
predictor was type of illness. Kaplan-Meier estimation was used to estimate patient survival time following referral, Cox proportional hazards regression was used to build predictive models based on gender, age, race, religion, and types of illnesses, and paired t-test compared the assessment of pain before and after referral. RESULTS: The cohort consisted of 256 children. Survival experience did not differ significantly based on gender, age, race, or religion (p >/= 0.05); however, survival did vary based on referring diagnosis (chi2 = 40.3, df = 4, p < 0.001), particularly cancer. Forty-eight children with three days of pain assessments pre- and postreferral had significantly decreased pain postreferral (t(47) = 1.816, p < 0.05 one tailed), supporting our hypothesis. DISCUSSION: Results provide important information on the complexity of disease processes for children referred to palliative care, types of illnesses referred, survival, and pain levels. Results reflect earlier referral to palliative care for most children and highlight the medical complexity especially for children with congenital and genetic diagnoses.


An estimated 175,000 cases of cancer are diagnosed annually in children younger than 15 years of age worldwide, and fewer than 40% of them, mostly in high-income countries, are adequately diagnosed and treated. A child’s probability of surviving cancer is poor in less developed countries, and extreme discomfort is likely in the absence of palliative care.


BACKGROUND AND OBJECTIVES: Health care use and cost for children at the end of life is not well documented across the multiple sectors where children receive care. The study objective was to examine demographics, location, cause of death, and health care use and costs over the last year of life for children aged 1 month to 19 years who died in Ontario, Canada. METHODS: We conducted a population-based retrospective cohort study using administrative databases to determine the characteristics of and health care costs by age group and cause of death over a 3-year period from 2010 to 2013. RESULTS: In our cohort of 1620 children, 41.6% died of a chronic disease with wide variation across age groups. The mean health care cost over the last year of life was $78 332 (Canadian) with a median of $18 450, reflecting the impact of high-cost decedents. The mean costs for children with chronic or perinatal/congenital illnesses nearly tripled over the last 4 months of life. The majority of costs (67.0%) were incurred in acute care settings, with 88.0% of children with a perinatal/congenital illness and 79.7% with a chronic illness dying in acute care. Only 33.4% of children received home care in the last year of life. CONCLUSIONS: Children in Ontario receive the majority of their end-of-life care in acute care settings at a high cost to the health care system. Initiatives to optimize care should focus on early discussion of the goals of care and assessment of whether the care provided fits with these goals.

INTRODUCTION: We evaluated outcomes in children with chronic kidney disease stage 5 (CKD 5) treated in the first pediatric dialysis unit in Poland during 1973-2012. MATERIAL AND METHODS: The retrospective analysis included 208 children with CKD 5 undergoing renal replacement therapy (RRT), stratified into four decades of treatment: 1973-1982, 1983-1992, 1993-2002, and 2003-2012. RESULTS: The most common causes of CKD 5 included glomerulonephritis in 27.4% and pyelonephritis secondary to urinary tract anomalies in 25.5% of children. Among 208 children, 172 (82.7%) survived and 17.3% died. Kidney transplantation (KTx) was performed in 47.6% of children, including pre-emptive KTx in 1.92% of children. Chronic dialysis was continued in 34.1% of children, and RRT was withdrawn in 1%. The overall mortality rate was 6.2 per 100 patient-years, and 3-year survival was 83.9%. The highest mortality rate of 23.4 per 100 patient-years was observed among children in whom RRT was initiated in 1973-1982, with subsequent reduction of the mortality rate to 4.5 and 2.1 per 100 patient-years in 1993-2002 and 1983-1992 respectively. No deaths were noted after 2002. Cardiovascular problems were the most common cause of death, found in 36.1% of patients (p < 0.01). Identified risk factors for mortality included young age, low residual diuresis, anemia at the time of RRT initiation, and hypertriglyceridemia and hypoalbuminemia during RRT. CONCLUSIONS: In years 1973-2012 significant improvement in prognosis among children with CKD 5 was achieved. Identified predictors of mortality included young age at initiation of RRT, low residual diuresis, anemia and hypertriglyceridemia.


OBJECTIVE: The present study aimed to investigate the factor structure and psychometric properties of the Cohen-Hoberman inventory of physical symptoms (CHIPS). Construct and discriminant validity were examined by assessing associations between factors and subjective health complaints (SHC) inventory subscales in addition to measures of pain sensitivity, perceived stress and psychological distress. DESIGN: A cross-sectional online survey was conducted with 535 healthy individuals from the general population (80.6% female, mean age = 29.80). MAIN OUTCOME MEASURES: Participants completed CHIPS, SHC, perceived stress scale, pain sensitivity questionnaire, and hospital anxiety and depression scale. RESULTS: Principal components analysis demonstrated that CHIPS comprised 8 'symptoms' factors as follows; 'sympathetic/cardiac' (7 items; alpha = .827), 'muscular' (6 items; alpha = .752), 'metabolic' (5 items; alpha = .736), 'gastrointestinal' (5 items; alpha = .714), 'vasovagal' (4 items; alpha = .743), 'cold/flu' (2 items; alpha = .837), 'headache' (2 items; alpha = .690) and 'minor hemorrhagic' (2 items; alpha = .309). Significant correlations were observed between factors and SHC subscales (moderate-high), pain sensitivity (negligible-low) and levels of perceived stress and anxiety (low-moderate) indicating good construct, and discriminant validity, respectively. CONCLUSIONS: CHIPS is a multidimensional and internally consistent measurement of physical symptoms. The postulated factor structure may be used for research purposes particularly in health psychology, to consistently differentiate between clusters of self-reported symptoms.


OBJECTIVE: The present study aimed to investigate the factor structure and psychometric properties of the Cohen-Hoberman inventory of physical symptoms (CHIPS). Construct and discriminant validity were examined by assessing associations between factors and subjective health complaints (SHC) inventory subscales in addition to measures of pain sensitivity, perceived stress and psychological distress. DESIGN: A cross-sectional online survey was conducted with 535 healthy individuals from the general population (80.6% female, mean age = 29.80). MAIN OUTCOME MEASURES: Participants completed CHIPS, SHC, perceived stress scale, pain sensitivity questionnaire, and hospital anxiety and depression scale. RESULTS: Principal components analysis demonstrated that CHIPS comprised 8 'symptoms' factors as follows; 'sympathetic/cardiac' (7 items; alpha = .827), 'muscular' (6 items; alpha = .752), 'metabolic' (5 items; alpha = .736), 'gastrointestinal' (5 items; alpha = .714), 'vasovagal' (4 items; alpha = .743), 'cold/flu' (2 items; alpha = .837), 'headache' (2 items; alpha = .690) and 'minor hemorrhagic' (2 items; alpha = .309). Significant correlations were observed between factors and SHC subscales (moderate-high), pain sensitivity (negligible-low) and levels of perceived stress and anxiety (low-moderate) indicating good construct, and discriminant validity, respectively. CONCLUSIONS: CHIPS is a multidimensional and internally consistent measurement of physical symptoms. The postulated factor structure may be used for research purposes particularly in health psychology, to consistently differentiate between clusters of self-reported symptoms.


BACKGROUND: Valid observational pain scales are needed to assess pain and ensure sufficient
treatment of pain in children that lack the verbal ability to self-report pain. Published reviews attempt to
synthesize results from primary studies validating these scales and based on the findings
recommendations may be given, for example which pain scales are the most appropriate for use in
different pediatric populations. OBJECTIVES: The aims of this review were to describe how systematic
reviews have evaluated and recommended observational pain scales for use in children aged 0-18 years
and appraise the evidence underlying these recommendations. DESIGN: Systematic review of reviews.
DATA SOURCES: The Cochrane Library, PubMed/MEDLINE, CINAHL, Web of Science, and PsychINFO
were searched from inception to September 2016. Reference lists and gray literature were searched for
additional studies. REVIEW METHODS: Study selection and data extraction were performed by two
reviewers independently with a disagreement procedure in place. Methodological quality or study validity
was measured using the Assessment of Multiple Systematic Reviews (AMSTAR) checklist and risk of
bias or internal validity was measured using the Risk of Bias in Systematic Reviews (ROBIS) tool. The
review protocol was registered with PROSPERO: registration number CRD42016035264. RESULTS:
Twelve reviews met the inclusion criteria. Together; they included 65 different observational pain scales
for use in children, of which 28 were recommended at least once. Face, Legs, Activity, Cry, Consolability
(FLACC)/revised version of Face, Legs, Activity, Cry, Consolability (rFLACC), COMFORT/COMFORT
behavioral scale and Children's Hospital of Eastern Ontario Pain Scale (CHEOPS) were evaluated and
recommended most frequently. Few of the included reviews assessed the methodological quality of the
studies included in the review. The narrative analysis consisted mostly of a reiteration of the results from
the primary studies. In general, more recent reviews showed a lower risk of bias than older ones.
CONCLUSIONS: Included reviews exhibited low quality of evidence; thus, their recommendations
regarding pain scales for use in clinical practice or research with children that lack the verbal ability to
self-report pain should be interpreted with caution.

Gabapentin Use in Neonates-Case Study and Review." Child Neurol Open 4: 2329048x17693123.

Visceral hyperalgesia refers to increased pain sensation in response to gastrointestinal sensory stimulus.
In neonates with neurological impairments, gabapentin has been successfully used as a treatment for
visceral hyperalgesia in neonates. The authors describe a preterm infant with myelomeningocele and
persistent neuropathic pain that manifested as irritability, hypertonicity, poor weight gain, and feeding
intolerance. After exclusion of other etiologies, the diagnosis of visceral hyperalgesia was suspected and
the infant was treated with gabapentin. Following appropriate titration to effect and close monitoring of
side effects of gabapentin, he subsequently demonstrated improved tone, decreased irritability with
feedings, and appropriate weight gain. In addition, the authors provide a review of the available literature
of gabapentin use in neonates and offer suggestions on when to consider starting gabapentin in a
neonate with neurological impairment and chronic unexplained gastrointestinal manifestations.

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Daniels and B. W. McCrindle (2017). "Longitudinal Outcomes of Patients With Single Ventricle After
the Fontan Procedure." J Am Coll Cardiol 69(22): 2735-2744.

BACKGROUND: Multicenter longitudinal objective data for survival into adulthood of patients who have
undergone Fontan procedures are lacking. OBJECTIVES: This study sought to describe transplant-free
survival and explore relationships between laboratory measures of ventricular performance and functional
status over time. METHODS: Exercise testing, echocardiography, B-type natriuretic peptide, functional
health assessment, and medical history abstraction were repeated 9.4 +/- 0.4 years after the Fontan
Cross-Sectional Study (Fontan 1) and compared with previous values. Cox regression analysis explored
risk factors for interim death or cardiac transplantation. RESULTS: From the original cohort of 546
subjects, 466 were contacted again, and 373 (80%) were enrolled at 21.2 +/- 3.5 years of age. Among
subjects with paired testing, the percent predicted maximum oxygen uptake decreased (69 +/- 14% vs. 61 +/- 16%; p < 0.001; n = 95), ejection fraction decreased (58 +/- 11% vs. 55 +/- 10%; p < 0.001; n = 259), and B-type natriuretic peptide increased (median [interquartile range] 13 [7 to 25] pg/mol vs. 18 [9 to 36] pg/mol; p < 0.001; n = 340). At latest follow-up, a lower Pediatric Quality of Life Inventory physical summary score was associated with poorer exercise performance (R2 adjusted = 0.20; p < 0.001; n = 274). Cumulative complications since the Fontan procedure included additional cardiac surgery (32%), catheter intervention (62%), arrhythmia treatment (32%), thrombosis (12%), and protein-losing enteropathy (8%). Since Fontan 1, 54 subjects (10%) have received a heart transplant (n = 23) or died without transplantation (n = 31). The interval risk of death or cardiac transplantation was associated with poorer ventricular performance and functional health status assessed at Fontan 1, but it was not associated with ventricular morphology, the subject’s age, or the type of Fontan connection.

CONCLUSIONS: Interim transplant-free survival over 12 years in this Fontan cohort was 90% and was independent of ventricular morphology. Exercise performance decreased and was associated with worse functional health status. Future interventions might focus on preserving exercise capacity. (Relationship Between Functional Health Status and Ventricular Performance After Fontan-Pediatric Heart Network; NCT00132782).


BACKGROUND: The 2016 World Health Organization (WHO) consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection, recommended to start all HIV-infected children on antiretroviral therapy (ART). Here, we explore the possible benefits and risks of implementing universal ART for all HIV-infected children and adolescents and outline some of the key considerations that led to the 2016 revision of WHO guidelines. METHODS: We conducted a review of the published data from 2000 to 2016, to ascertain the clinical and programmatic benefits, as well as the risks of implementing universal ART for all children. RESULTS AND DISCUSSION: Universal ART for all children has the potential to increase treatment coverage, which in 2015 was only 51% globally, as well as providing several biological benefits, by preventing: premature death/loss to follow-up, progressive destruction of the immune system, poor growth and pubertal delay, poor neuro-cognitive outcomes and future burden to the health care system with complications of untreated HIV-infection. However, the strategy could be associated with risks, notably development of HIV drug resistance, antiretroviral drug toxicities and increased costs to an already stretched health system. CONCLUSION: Overall, our findings suggest that the benefits could outweigh the risks and support universal ART for all HIV-infected children, but recognize that national programmes will need to put measures in place to minimize the risks if they choose to implement the strategy.


BACKGROUND: Asthma is the most common obstructive airway disease in children and adults. Nasal high flow (NHF) is a recent device that is now used as a primary support for respiratory distress. Several studies have reported use of NHF as a respiratory support in status asthmaticus; however, there are no data to recommend such practice. We therefore conducted this preliminary study to evaluate NHF therapy for children with status asthmaticus admitted to our PICU in order to prepare a multicentre randomized controlled study. RESULTS: Between November 2009 and January 2014, 73 patients with status asthmaticus were admitted to the PICU, of whom 39 (53%) were treated with NHF and among these 10 (26%) presented severe acidosis at admission (pH < 7.30). Thirty-four less severe children (41%) were treated with standard oxygen. For one child (2.6%) NHF failed and was then switched to non-invasive ventilation. NHF was discontinued in another patient because of the occurrence of pneumothorax after 31 h with NHF; the patient was then switched to standard oxygen therapy. Mean +/-
SD heart rate (165 +/- 21 vs. 141 +/- 25/min, p < 0.01) and respiratory rate (40 +/- 13 vs. 31 +/- 8/min, p < 0.01) decreased significantly, and blood gas improved in the first 24 h. In the subgroup of patients with acidosis, median [IQR] pH increased significantly between hour 0 and 2 (7.25 [7.21-7.26] vs. 7.30 [7.27-7.33], p = 0.009) and median [IQR] pCO2 decreased significantly (7.27 kPa [6.84-7.91 vs. 5.85 kPa [5.56-6.11], p = 0.007). No patient was intubated. CONCLUSION: This retrospective study showed the feasibility and safety of NHF in children with severe asthma. Blood gas and clinical parameters were significantly improved during the first 24 h. NHF failed in only two patients, and none required invasive ventilation.


PURPOSE OF REVIEW: High-fat, low-carbohydrate ketogenic diets have been used for almost a century for the treatment of epilepsy. Used traditionally for the treatment of refractory pediatric epilepsies, in recent years the use of ketogenic diets has experienced a revival to include the treatment of adulthood epilepsies as well as conditions ranging from autism to chronic pain and cancer. Despite the ability of ketogenic diet therapy to suppress seizures refractory to antiepileptic drugs and reports of lasting seizure freedom, the underlying mechanisms are poorly understood. This review explores new insights into mechanisms mobilized by ketogenic diet therapies.

RECENT FINDINGS: Ketogenic diets act through a combination of mechanisms, which are linked to the effects of ketones and glucose restriction, and to interactions with receptors, channels, and metabolic enzymes. Decanoic acid, a component of medium-chain triacylglycerides, contributes to seizure control through direct alpha-amino-3-hydroxy-5-methyl-4-isoxazolepropionic acid (AMPA) receptor inhibition, whereas drugs targeting lactate dehydrogenase reduce seizures through inhibition of a metabolic pathway. Ketogenic diet therapy also affects DNA methylation, a novel epigenetic mechanism of the diet.

SUMMARY: Ketogenic diet therapy combines several beneficial mechanisms that provide broad benefits for the treatment of epilepsy with the potential to not only suppress seizures but also to modify the course of the epilepsy.


OBJECTIVE: To investigate the feasibility, safety, and efficacy of a ketogenic diet (KD) for superrefractory status epilepticus (SRSE) in adults. METHODS: We performed a prospective multicenter study of patients 18 to 80 years of age with SRSE treated with a KD treatment algorithm. The primary outcome measure was significant urine and serum ketone body production as a biomarker of feasibility. Secondary measures included resolution of SRSE, disposition at discharge, KD-related side effects, and long-term outcomes. RESULTS: Twenty-four adults were screened for participation at 5 medical centers, and 15 were enrolled and treated with a classic KD via gastrostomy tube for SRSE. Median age was 47 years (interquartile range [IQR] 30 years), and 5 (33%) were male. Median number of antiseizure drugs used before KD was 8 (IQR 7), and median duration of SRSE before KD initiation was 10 days (IQR 7 days). KD treatment delays resulted from intravenous propofol use, ileus, and initial care received at a nonparticipating center. All patients achieved ketosis in a median of 2 days (IQR 1 day) on KD. Fourteen patients completed KD treatment, and SRSE resolved in 11 (79%; 73% of all patients enrolled). Side effects included metabolic acidosis, hyperlipidemia, constipation, hypoglycemia, hyponatremia, and weight loss. Five patients (33%) ultimately died. CONCLUSIONS: KD is feasible in adults with SRSE and may be safe and effective. Comparative safety and efficacy must be established with randomized placebo-controlled trials.

CLASSIFICATION OF EVIDENCE: This study provides Class IV evidence that in adults with SRSE, a KD is effective in inducing ketosis.

OBJECTIVE: There is increasing recognition that socio-cognitive skills, such as moral reasoning (MR), are affected in a wide range of developmental and neuropsychological conditions. However, the lack of appropriate measures available to neuropsychologists poses a challenge for the direct assessment of these skills. This study sought to explore age-related changes in MR using an innovative visual tool and examine the developmental sensitivity of the task. METHOD: To address some of the methodological limitations of traditional measures of MR, a novel, visual task, the Socio-Moral Reasoning Aptitude Level (So-Moral), was used to evaluate MR in 216 healthy participants aged 6-20 years. RESULTS: The findings show a linear increase in MR from childhood to late adolescence with significant group differences between childhood (6-8 years) and preadolescence (9-11 years), and between early adolescence (12-14 years) and middle adolescence (15-17 years). CONCLUSIONS: Interpreted in light of current brain development research, the results highlight age-related changes in MR that offer insight into typical MR development and opportunities for comparisons with clinical populations. The findings also provide evidence of the potential of the So-Moral as a developmentally appropriate measure of MR throughout childhood and adolescence.


OBJECTIVE: To describe the implementation of a nurse-led project to screen parents for depression and traumatic stress in the postpartum period after visiting their newborns in the NICU. DESIGN: A standardized universal mental health postpartum screening and referral protocol was developed for parents of high-risk neonates. SETTING/LOCAL PROBLEM: The project occurred at the Garbose Family Special Delivery Unit, the first high-risk obstetrics unit serving healthy women who give birth to newborns with prenatally diagnosed fetal anomalies. Parents of neonates admitted to the NICU are at greater risk to develop postpartum psychological distress; therefore, early identification is critical. PATIENTS: A total of 1,327 participants were screened, including 725 women who gave birth to live newborns at the Garbose Family Special Delivery Unit and 602 partners. INTERVENTION/MEASUREMENTS: Obstetric nurses asked parents to complete a screening tool that assessed their psychological risk in the postpartum period. A system for mental health triage and referral was available for parents with elevated scores. RESULTS: Overall monthly screening procedure compliance rates were high (96.5% mothers and 79.6% partners). Women (5.5%, n = 40) and men (5.5%, n = 33) showed high risk for traumatic stress, and 35.9% (n = 260) of women and 9.5% (n = 57) of men showed elevated risk for major depression in the immediate postpartum period. CONCLUSION: Incorporating the screening process into routine nursing practice with immediate mental health triage and referral made the program feasible. The risk factors identified add to the growing knowledge about parents of newborns in the NICU.


OBJECTIVE: To systematically identify health-related quality-of-life outcome measures that could be used in paediatric palliative care and examine their feasibility of use.

BACKGROUND: The number of children worldwide requiring palliative care services is increasing due to advances in medical care and technology. The use of outcome measures is important to improve the quality and effectiveness of care. AIM: To systematically identify health-related quality-of-life outcome measures that could be used in paediatric palliative care and examine their feasibility of use and
psychometric properties. DESIGN: A systematic literature review and analysis of psychometric properties. DATA SOURCES: PsychInfo, Medline and EMBASE were searched from 1 January 1990 to 10 December 2014. Hand searches of the reference list of included studies and relevant reviews were also performed. RESULTS: From 3460 articles, 125 papers were selected for full-text assessment. A total of 41 articles met the eligibility criteria and examined the psychometric properties of 22 health-related quality-of-life measures. Evidence was limited as at least half of the information on psychometric properties per instrument was missing. Measurement error was not analysed in any of the included articles and responsiveness was only analysed in one study. The methodological quality of included studies varied greatly. CONCLUSION: There is currently no 'ideal' outcome assessment measure for use in paediatric palliative care. The domains of generic health-related quality-of-life measures are not relevant to all children receiving palliative care and some domains within disease-specific measures are only relevant for that specific population. Potential solutions include adapting an existing measure or developing more individualized patient-centred outcome and experience measures. Either way, it is important to continue work on outcome measurement in this field.


BACKGROUND AND OBJECTIVE: Small pilot studies support the appropriateness of engaging adolescents with chronic or life-limiting illnesses in pediatric advance care planning (pACP). We do not yet know if pACP is acceptable, feasible, and worthwhile, even if emotionally intense, in a fully powered randomized controlled trial. METHODS: We conducted a prospective 2-arm randomized controlled trial at 6 US urban hospitals. Adolescent/family member dyads were randomized to receive the 1-session-a-week 3-session FAmily-CEntered Advance Care Planning (FACE) pACP intervention (1, ACP Survey; 2, Goals of Care Conversation/Treatment Preferences; 3, Completion of Advance Directive) or active comparator (1, Developmental History; 2, Safety Tips; 3, Nutrition/Exercise). The Satisfaction Questionnaire was administered to participants independently after each session by a blinded research assistant. RESULTS: We enrolled 53% of eligible participants and intervened with 97 adolescent/family dyads. Adolescents ranged in age from 14 to 21 years; 54% were male individuals; 93% African American; and 73% perinatally infected. Attendance was 99% for all 3 sessions in each arm. At session 3, FACE adolescents and family dyad members, respectively, found the session useful (98%, 98%) and helpful (98%, 100%), despite feelings of sadness (25%, 17%). FACE adolescents' improvement in the total subscale A score (useful, helpful, like a load off my mind, satisfied, something I needed to do, courageous, worthwhile) was better than control adolescents at session 3 (beta = 1.16, P = .02). There were no adverse events. CONCLUSIONS: FACE enabled worthwhile conversations, while simultaneously eliciting intense emotions. No participants withdrew, 99% of those enrolled completed each session, and there were no adverse events, evidence of pACP's feasibility, acceptability, and safety.


BACKGROUND: Childhood and adolescent cancers are uncommon, but they have important economic and health impacts on patients, families, and health care systems. Few studies have measured the economic burden of care for childhood and adolescent cancers. OBJECTIVES: To estimate costs of cancer care in population-based cohorts of children and adolescents from the public payer perspective. METHODS: We identified patients with cancer, aged 91 days to 19 years, diagnosed from 1995 to 2009 using cancer registry data, and matched each to three noncancer controls. Using linked administrative health care records, we estimated total and net resource-specific costs (in 2012 Canadian dollars) during
90 days prediagnosis and 1 year postdiagnosis. RESULTS: Children (\(
\leq 14\) years old) numbered 4,396: 36\% had leukemia, 21\% central nervous system tumors, 10\% lymphoma, and 33\% other cancers. Adolescents (15-19 years old) numbered 2,329: 28.9\% had lymphoma. Bone and soft tissue sarcoma, germ cell tumor, and thyroid carcinoma each comprised 12\% to 13\%. Mean net prediagnosis costs were $5,810 and $1,127 and mean net postdiagnosis costs were $136,413 and $62,326 for children and adolescents, respectively; the highest were for leukemia ($157,764 for children and $172,034 for adolescents). In both cohorts, costs were much higher for patients who died within 1 year of diagnosis. Inpatient hospitalization represented 69\% to 74\% of postdiagnosis costs. CONCLUSIONS: Treating children with cancer is costly, more costly than treating adolescents or adults. Substantial survival gains in children mean that treatment may still be very cost-effective. Comprehensive age-specific population-based cost estimates are essential to reliably assess the cost-effectiveness of cancer care for children and adolescents, and measure health system performance.


Traditional and complementary medicine (T&CM) strategies are widely utilized in pediatric oncology, with many families reporting T&CM use with the intention to cure cancer. Study of T&CM agents presents many challenges, as a heterogeneous group of agents and techniques are used for a variety of different purpose in many different oncologic conditions. We present a systematic review of the literature examining published reports in which T&CM agents are used with an intention of cure. Twenty-two reports were identified, with most reports being of poor quality. Novel paradigms are likely needed to further investigate T&CM agents. https://www.ncbi.nlm.nih.gov/pubmed/28244653


BACKGROUND: There is an increasing need to assess the evidence of a multidisciplinary approach for both short-term and long-term management of neurological sequelae arising from the diagnosis and treatment of brain tumors in childhood. METHODS: We performed a systematic review of the evidence base for multidisciplinary paediatric brain tumor rehabilitation using seven databases. PRISMA guidelines were adhered to and the review was registered with the PROSPERO international prospective register of systematic reviews (registration number CRD42014015070). RESULTS: The literature search identified 3,061 results. Three service evaluations were included. The review identified limited evidence in favor of multidisciplinary rehabilitation for children with brain tumors. Due to the lack of controlled trial data and heterogeneity of the interventions and outcome measures, no meta-analysis could be performed. CONCLUSIONS: Studies utilising a coordinated multi-centre approach with standardized outcome measures are recommended in order to enable robust assessment of the efficacy of multidisciplinary rehabilitation services. https://www.ncbi.nlm.nih.gov/pubmed/26222675


PURPOSE: To describe the clinical features of electric powered indoor/outdoor wheelchair users with a muscular dystrophy, likely to influence optimal prescription; reflecting features of muscular dystrophies, conditions secondary to disability, and comorbidities impacting on equipment provision. METHODS: Cross-sectional retrospective case note review of recipients of electric powered indoor/outdoor wheelchairs provided by a specialist regional wheelchair service. Data on demography, diagnostic/clinical, and wheelchair prescription were systematically extracted. RESULTS: Fifty-one men and 14 women, mean age 23.7 (range 10-67, s.d. 12.95) years, were studied. Forty had Duchenne muscular dystrophy, 22 had other forms of muscular dystrophy, and three were unclassified. Twenty-
seven were aged under 19. Notable clinical features included problematic pain (10), cardiomyopathy (5), and ventilatory failure (4). Features related to disability were (kypho)scoliosis (20) and edema/cellulitis (3) whilst comorbidities included back pain (5). Comparison of younger with older users revealed younger users had more features of muscular dystrophy affecting electric powered chair provision (56%) whilst older users had more comorbidity (37%). Tilt-in-space was prescribed for 81% of users, specialized seating for 55% and complex controls for 16%. CONCLUSIONS: Muscular dystrophy users were prescribed electric powered indoor/outdoor chairs with many additional features reflecting the consequences of profound muscle weakness. In addition to facilitating independence and participation, electric powered indoor/outdoor chairs have major therapeutic benefits. Implications for rehabilitation Powered wheelchairs have therapeutic benefits in managing muscular dystrophy pain and weakness. The use of specialized seating needs careful consideration in supporting progressive muscle weakness and the management of scoliosis. Pain, discomfort, pressure risk, and muscle fatigue may be reduced by use of tilt-in-space.


PURPOSE: Status epilepticus (SE) is a neurological emergency, characterized by high short-term morbidity and mortality. We evaluated and compared two scores that have been developed to evaluate status epilepticus prognosis: STESS (Status Epilepticus Severity Score) and EMSE (Epidemiology based Mortality score in Status Epilepticus). METHODS: A prospective observational study was performed on consecutive patients with SE admitted between September 2013 and August 2015. Demographics, clinical variables, STESS-3 and -4, and EMSE-64 scores were calculated for each patient at baseline. SE drug response, 30-day mortality and morbidity were the outcomes measure. RESULTS: 162 episodes of SE were observed: 69% had a STESS >/=3; 34% had a STESS >/=4; 51% patients had an EMSE >/=64. The 30-days mortality was 31.5%: EMSE-64 showed greater negative predictive value (NPV) (97.5%), positive predictive value (PPV) (59.8%) and accuracy in the prediction of death than STESS-3 and STESS-4 (p<0.001). At 30 days, the clinical condition had deteriorated in 59% of the cases: EMSE-64 showed greater NPV (71.3%), PPV (87.8%) and accuracy than STESS-3 and STESS-4 (p<0.001) in the prediction of this outcome. In 23% of all cases, status epilepticus proved refractory to non-anaesthetic treatment. All three scales showed a high NPV (EMSE-64: 87.3%; STESS-4: 89.4%; STESS-3: 87.5%) but a low PPV (EMSE-64: 40.9%; STESS-4: 52.9%; STESS-3: 32%) for the prediction of refractoriness to first and second line drugs. This means that accuracy for the prediction of refractoriness was equally poor for all scales. CONCLUSIONS: EMSE-64 appears superior to STESS-3 and STESS-4 in the prediction of 30-days mortality and morbidity. All scales showed poor accuracy in the prediction of response to first and second line antiepileptic drugs. At present, there are no reliable scores capable of predicting treatment responsiveness.


OBJECTIVE: This study developed and piloted an educational intervention to support healthcare professionals (HCPs) to provide supportive care for families when a parent has cancer. METHODS: Programme development followed the Medical Research Council (MRC) framework, beginning with examination of theory and research, and consultation with experts. The programme content incorporated attachment theory, child development and family systems theory. It was piloted thrice with HCPs from a cancer centre. The evaluation involved a questionnaire, comprising open-ended questions, completed before and after the programme. Data from the questionnaire were analysed using framework analysis. RESULTS: 31 HCPs from varying disciplines participated. The programme was evaluated positively by participants. Before the programme, participants had significant concerns about their professional competence, which included: managing their own emotions; a perceived sensitivity around raising child
and family matters with patients and a lack of specialist experience, skills and knowledge. After completing the programme, participants reported greater understanding and knowledge, increased confidence to approach patients about family matters, greater skill to initiate conversations and explore family concerns and guiding parent-child communication according to the child’s level of understanding, and an increased engagement and resilience for caring for parents with cancer. SIGNIFICANCE OF THE RESULTS: Supporting HCPs to provide family-centred care is likely to reduce psychological difficulties in families where a parent has cancer. Further work is planned to disseminate the programme, evaluate the transfer of skills into practice, assess how HCPs manage the emotional demands of providing supportive care over time, and consider on-going professional support for HCPs.


BACKGROUND AND OBJECTIVES: Despite significant morbidity and mortality associated with ESRD, these patients receive palliative care services much less often than patients with other serious illnesses, perhaps because they are perceived as having less need for such services. We compared characteristics and outcomes of hospitalized patients in the United States who had a palliative care consultation for renal disease versus other serious illnesses. DESIGN, SETTING, PARTICIPANTS, & MEASUREMENTS: In this observational study, we used data collected by the Palliative Care Quality Network, a national palliative care quality improvement collaborative. The 23-item Palliative Care Quality Network core dataset includes demographics, processes of care, and clinical outcomes of all hospitalized patients who received a palliative care consultation between December of 2012 and March of 2016. RESULTS: The cohort included 33,183 patients, of whom 1057 (3.2%) had renal disease as the primary reason for palliative care consultation. Mean age was 71.9 (SD=16.8) or 72.8 (SD=15.2) years old for those with renal disease or other illnesses, respectively. At the time of consultation, patients with renal disease or other illnesses had similarly low mean Palliative Performance Scale scores (36.0% versus 34.9%, respectively; P=0.08) and reported similar moderate to severe anxiety (14.9% versus 15.3%, respectively; P=0.90) and nausea (5.9% versus 5.9%, respectively; P>0.99). Symptoms improved similarly after consultation regardless of diagnosis (P>0.50), except anxiety, which improved more often among those with renal disease (92.0% versus 66.0%, respectively; P=0.002). Although change in code status was similar among patients with renal disease versus other illnesses, from over 60% full code initially to 30% full code after palliative care consultation, fewer patients with renal disease were referred to hospice than those with other illnesses (30.7% versus 37.6%, respectively; P<0.001). CONCLUSIONS: Hospitalized patients with renal disease referred for palliative care consultation had similar palliative care needs, improved symptom management, and clarification of goals of care as those with other serious illnesses.


BACKGROUND: Empirically derived and tested models are necessary to develop effective, holistic interventions to improve positive health outcomes in adolescents and young adults (AYA) with cancer, yet few exist. This article is the second of 2 articles reporting on evaluation of the Resilience in Illness Model (RIM) as a predictive model to guide positive health research and practice. OBJECTIVE: The aim of this study was to report the confirmatory model evaluation of the RIM. METHODS: A confirmatory evaluation of RIM was done using baseline data from a sample of 113 AYA aged 11 to 24 years who were undergoing hematopoietic stem cell transplant and enrolled in a randomized controlled trial of a behavioral intervention to enhance resilience. Data were analyzed using latent variable structural equation modeling. RESULTS: Goodness-of-fit indices supported RIM as a confirmed model that accounted for large amounts of variance in the outcomes of self-transcendence (62%) and resilience (72%), and in 3 of 5 mediators, specifically social integration (74%), courageous coping (80%), and hope-derived meaning.
(87%), as well as small to moderate amounts of variance in the remaining mediators of defensive coping (1%) and family environment (35%). CONCLUSIONS: Findings establish the RIM as a plausible predictive framework for explaining ways AYA with cancer transcend their illness and achieve resilience resolution and for guiding intervention studies in this population. Additional research is needed to explore RIM’s transferability based on stage of illness, other chronic diseases, and cultural diversity. IMPLICATIONS FOR PRACTICE: Results support the RIM as an appropriate guide for developing and evaluating interventions to foster positive adjustment in AYA with cancer.


BACKGROUND: Duchenne muscular dystrophy (DMD) is a rare disease that causes the progressive loss of motor abilities such as walking. Standard treatment includes physiotherapy. No trial has evaluated whether or not adding aquatic therapy (AT) to land-based therapy (LBT) exercises helps to keep muscles strong and children independent. OBJECTIVES: To assess the feasibility of recruiting boys with DMD to a randomised trial evaluating AT (primary objective) and to collect data from them; to assess how, and how well, the intervention and trial procedures work. DESIGN: Parallel-group, single-blind, randomised pilot trial with nested qualitative research. SETTING: Six paediatric neuromuscular units. PARTICIPANTS: Children with DMD aged 7-16 years, established on corticosteroids, with a North Star Ambulatory Assessment (NSAA) score of 8-34 and able to complete a 10-m walk without aids/assistance. Exclusions: > 20% variation between baseline screens 4 weeks apart and contraindications. INTERVENTIONS: Participants were allocated on a 1:1 ratio to (1) optimised, manualised LBT (prescribed by specialist neuromuscular physiotherapists) or (2) the same plus manualised AT (30 minutes, twice weekly for 6 months: active assisted and/or passive stretching regime; simulated or real functional activities; submaximal exercise). Semistructured interviews with participants, parents (n = 8) and professionals (n = 8) were analysed using Framework analysis. An independent rater reviewed patient records to determine the extent to which treatment was optimised. A cost-impact analysis was performed. Quantitative and qualitative data were mixed using a triangulation exercise. MAIN OUTCOME MEASURES: Feasibility of recruiting 40 participants in 6 months, participant and therapist views on the acceptability of the intervention and research protocols, clinical outcomes including NSAA, independent assessment of treatment optimisation and intervention costs. RESULTS: Over 6 months, 348 children were screened - most lived too far from centres or were enrolled in other trials. Twelve (30% of target) were randomised to AT (n = 8) or control (n = 4). People in the AT (n = 8) and control (n = 2: attrition because of parental report) arms contributed outcome data. The mean change in NSAA score at 6 months was -5.5 [standard deviation (SD) 7.8] for LBT and -2.8 (SD 4.1) in the AT arm. One boy suffered pain and fatigue after AT, which resolved the same day. Physiotherapists and parents valued AT and believed that it should be delivered in community settings. The independent rater considered AT optimised for three out of eight children, with other children given programmes that were too extensive and insufficiently focused. The estimated NHS costs of 6-month service were between £1970 and £2734 per patient. LIMITATIONS: The focus on delivery in hospitals limits generalisability. CONCLUSIONS: Neither a full-scale frequentist randomised controlled trial (RCT) recruiting in the UK alone nor a twice-weekly open-ended AT course delivered at tertiary centres is feasible. Further intervention development research is needed to identify how community-based pools can be accessed, and how families can link with each other and community physiotherapists to access tailored AT programmes guided by highly specialised physiotherapists. Bayesian RCTs may be feasible; otherwise, time series designs are recommended. TRIAL REGISTRATION: Current Controlled Trials ISRCTN41002956. FUNDING: This project was funded by the National Institute for Health Research (NIHR) Health Technology Assessment programme and will be published in full in Health Technology Assessment; Vol. 21, No. 27. See the NIHR Journals Library website for further project information.


CONTEXT: Despite advances in therapies, many pediatric heart transplant (Htx) recipients will die prematurely. We characterized the circumstances surrounding death in this cohort, including location of death and interventions performed in the final 24 hours. METHODS: We reviewed all patients who underwent Htx at Lucile Packard Children’s Hospital, Stanford, survived hospital discharge, and subsequently died between July 19, 2007 and September 13, 2015. The primary outcome studied was location of death, characterized as inpatient, outpatient, or emergency department. Circumstances of death (withdrawal of life-sustaining treatment, death during resuscitation, or death without resuscitation with/without do not resuscitate) and interventions performed in the last 24 hours of life were also analyzed. RESULTS: Twenty-three patients met the entry criteria. The median age at death was 12 (range 2-20) years, and the median time between transplant and death was 2.8 (range 0.8-11) years. Four (17%) died at home, and three (13%) died in the emergency department. Sixteen (70%) patients died in the hospital, 14 of 16 (88%) of whom died in an intensive care unit. Five of 23 (22%) patients experienced attempted resuscitation. Interventions performed in the last 24 hours of life included intubation (74%), mechanical support (30%), and dialysis (22%). Most patients had a recent outpatient clinical encounter with normal graft function within 60 days of dying. CONCLUSIONS/LESSONS LEARNED: Death in children after Htx often occurs in the inpatient setting, particularly the intensive care unit. Medical interventions, including attempted resuscitation, are common at the end of life. Given the difficulty in anticipating life-threatening events, earlier discussions with patients regarding end-of-life wishes are appropriate, even in those with normal graft function.


PURPOSE: To describe a population choosing to continue their pregnancy despite a severe fetal abnormality and to evaluate the role of antenatal neonatology consultation in perinatal decision-making. METHODS: A 10-year (2005-2015) retrospective descriptive study in a single Multidisciplinary Prenatal Diagnosis Center in South France. A series of pregnancies with severe fetal abnormalities were collected by a person outside the decision making process and/or the child's care. RESULTS: Thirty-nine pregnancies were included, among which 12 couples chose the perinatal palliative care. In total, there were 25 live births (10 later died, with median of survival of 52.5 h [16-943.5]); only five infants received a palliative care plan at birth. CONCLUSION: The choice to continue a pregnancy diagnosed with severe fetal pathology is on the rise in France. Treatment options point to standardize perinatal palliative care provided by trained perinatal professionals using standardized practices.


OBJECTIVES: To describe the frequency of postnatal discussions about withdrawal or withholding of life-sustaining therapy (WWLST), ensuing WWLST, and outcomes of infants surviving such discussions. We hypothesized that such survivors have poor outcomes. STUDY DESIGN: This retrospective review included registry data from 18 centers of the National Institute of Child Health and Human Development Neonatal Research Network. Infants born at 22-28 weeks of gestation who survived >12 hours during 2011-2013 were included. Regression analysis identified maternal and infant factors associated with WWLST discussions and factors predicting ensuing WWLST. In-hospital and 18- to 26-month outcomes were evaluated. RESULTS: WWLST discussions occurred in 529 (15.4%) of 3434 infants. These were more frequent at 22-24 weeks (27.0%) compared with 27-28 weeks of gestation (5.6%). Factors
associated with WWLST discussion were male sex, gestational age (GA) of \( \leq 24 \) weeks, birth weight small for GA, congenital malformations or syndromes, early onset sepsis, severe brain injury, and necrotizing enterocolitis. Rates of WWLST discussion varied by center (6.4%-29.9%) as did WWLST (5.2%-20.7%). Ensuing WWLST occurred in 406 patients; of these, 5 survived to discharge. Of the 123 infants for whom intensive care was continued, 58 (47%) survived to discharge. Survival after WWLST discussion was associated with higher rates of neonatal morbidities and neurodevelopmental impairment compared with babies for whom WWLST discussions did not occur. Significant predictors of ensuing WWLST were maternal age >25 years, necrotizing enterocolitis, and days on a ventilator.

CONCLUSIONS: Wide center variations in WWLST discussions occur, especially at \( \leq 24 \) weeks GA. Outcomes of infants surviving after WWLST discussions are poor. TRIAL REGISTRATION: ClinicalTrials.gov: NCT00063063. https://www.ncbi.nlm.nih.gov/pubmed/28647272


Medium- and long-term outcomes have been collected and described among survivors of neonatal intensive care units for decades, for a number of purposes: (1) quality control within units, (2) comparisons of outcomes between NICUs, (3) clinical trials (whether an intervention improves outcomes), (4) end-of-life decision-making, (5) to better understand the effects of neonatal conditions and/or interventions on organs and/or long-term health, and finally (6) to better prepare parents for the future. However, the outcomes evaluated have been selected by investigators, based on feasibility, availability, cost, stability, and on what investigators consider to be important. Many of the routinely measured outcomes have major limitations: they may not correlate well with long-term difficulties, they may artificially divide continuous outcomes into dichotomous ones, and may have no clear relationship with quality of life and functioning of children and their families. Several investigations, such as routine term cerebral resonance imaging for preterm infants, have also not yet been shown to improve the outcome of children nor their families. In this article, the most common variables used in neonatology as well as some variables which are rarely measured but may be of equal importance for families are presented. The manner in which these outcomes are communicated to families will be examined, as well as recommendations to optimize communication with parents. https://www.ncbi.nlm.nih.gov/pubmed/27793420


Purpose Children with cancer often receive high-intensity (HI) medical care at the end-of-life (EOL). Previous studies have been limited to single centers or lacked detailed clinical data. We determined predictors of and trends in HI-EOL care by linking population-based clinical and health-services databases. Methods A retrospective decedent cohort of patients with childhood cancer who died between 2000 and 2012 in Ontario, Canada, was assembled using a provincial cancer registry and linked to population-based health-care data. Based on previous studies, the primary composite measure of HI-EOL care comprised any of the following: intravenous chemotherapy < 14 days from death; more than one emergency department visit; and more than one hospitalization or intensive care unit admission < 30 days from death. Secondary measures included those same individual measures and measures of the most invasive (MI) EOL care (eg, mechanical ventilation < 14 days from death). We determined predictors of outcomes with appropriate regression models. Sensitivity analysis was restricted to cases of cancer-related mortality, excluding treatment-related mortality (TRM) cases. Results The study included 815 patients; of these, 331 (40.6%) experienced HI-EOL care. Those with hematologic malignancies were at highest risk (odds ratio, 2.5; 95% CI, 1.8 to 3.6; \( P < .001 \)). Patients with hematologic cancers and those who died after 2004 were more likely to experience the MI-EOL care (eg, intensive care unit, mechanical ventilation, odds ratios from 2.0 to 5.1). Excluding cases of TRM did not substantively change the results. Conclusion Ontario children with cancer continue to experience HI-EOL
Patients with hematologic malignancies are at highest risk even when excluding TRM. Of concern, rates of the MI-EOL care have increased over time despite increased palliative care access. Linking health services and clinical data allows monitoring of population trends in EOL care and identifies high-risk populations for future interventions.


BACKGROUND: End-stage renal disease (ESRD) affects nearly 1400 new children each year in the United States. Morbidity and mortality rates remain high for pediatric patients with ESRD, including those that have received a renal transplant. OBJECTIVE: To better understand ESRD patients referred to palliative care, including their physical symptoms, topics discussed, and themes emerging during initial palliative care consultation. DESIGN/SUBJECTS: This study is a retrospective chart review of pediatric ESRD patients who received a palliative care consult. Physical symptoms, core topics, and themes were identified by the interprofessional study team. RESULTS: The study team found 35 patients met inclusion criteria during the study period. The most common standard palliative care metric noted was "complex or time-intensive communication and interdisciplinary social support." Pain was the most common physical symptom addressed with goals of care and communication the most common topics discussed. Themes emerging described the emotional distress of patients and parents as well as prognostic discussions. CONCLUSIONS: This study demonstrates one institution's experience with pediatric ESRD patients undergoing consultation with the pediatric palliative care service. More research is necessary in this population to better describe the best focus for palliative care teams.


BACKGROUND: The number of patients with congenital heart disease (CHD) is increasing worldwide and most of them will require cardiac surgery, once or more, during their lifetime. The total volume of cardiac surgery in CHD patients at a national level and the associated mortality and predictors of death associated with surgery are not known. We aimed to investigate the surgical volume and associated mortality in CHD patients in England. METHODS: Using a national hospital episode statistics database, we identified all CHD patients undergoing cardiac surgery in England between 1997 and 2015. RESULTS: We evaluated 57,293 patients (median age 11.9 years, 46.7% being adult, 56.7% female). There was a linear increase in the number of operations performed per year from 1,717 in 1997 to 5,299 performed in 2014. The most common intervention at the last surgical event was an aortic valve procedure (9,276; 16.2%), followed by repair of atrial septal defect (9,154; 16.0%), ventricular septal defect (7,746; 13.5%), tetralogy of Fallot (3,523; 6.1%) and atrioventricular septal defect (3,330; 5.8%) repair. Associated mortality remained raised up to six months following cardiac surgery. Several parameters were predictive of post-operative mortality, including age, complexity of surgery, need for emergency surgery and socioeconomic status. The relationship of age with mortality was "U"-shaped, and mortality was highest amongst youngest children and adults above 60 years of age. CONCLUSIONS: The number of cardiac operations performed in CHD patients in England has been increasing, particularly in adults. Mortality remains raised up to 6-months after surgery and was highest amongst young children and seniors.

PURPOSE: Gastrostomy is commonly used procedures to provide enteral nutrition support for severely handicapped patients. This study aimed to identify and compare outcomes and complications associated with percutaneous endoscopic gastrostomy (PEG) and surgical gastrostomy (SG).

METHODS: A retrospective chart review of 51 patients who received gastrostomy in a single tertiary hospital from January 2000 to May 2016 was performed. We analyzed the patients and the complications caused by the procedures. RESULTS: Among the 51 patients, 26 had PEG and 25 had SG. Four cases in the SG group had fundoplication for gastroesophageal reflux disease. PEG and SG groups were followed up for an average of 29 months and 44 months. Major complications occurred in 19.2% of patients in the PEG group and 20.0% in the SG group, but significant differences between the groups were not observed. Minor complications occurred in 15.4% of patients in the PEG group and 52.0% in the SG group. Minor complications were significantly lower in the PEG group than in the SG group (p=0.006). Thirteen patients died of underlying disease but not related to gastrostomy, and only one patient died due to complications associated with general anesthesia. CONCLUSION: The duration of antibiotics use and incidence of minor complications were significantly lower in the PEG group than those in the SG group. Early PEG could be recommended for nutritional supports.


OBJECTIVE: The Korean advance directive (K-AD) comprises a value statement, treatment directives, preferences for cardiopulmonary resuscitation (CPR), artificial ventilation, tube feeding, and hospice care, as well as a proxy appointment. The K-AD can facilitate a patient’s decision making with respect to end-of-life (EoL) care. The present study aimed to examine the extent to which patient-caregiver dyads would use the K-AD and agree on EoL care decisions. METHODS: Using a descriptive study design, 81 cancer patients were invited to participate. The final sample consisted of 44 patient-caregiver dyads who completed survey questionnaires, including the K-AD. One patient did not complete all parts of the questionnaire, and 36 (44.4%) declined to participate. Content analysis was conducted to examine the K-AD value statements. Cohen’s kappa coefficient was calculated to determine the degree of patient-caregiver dyadic agreement on K-AD treatment directives (Sudore & Fried, 2010). RESULTS: Our patient participants had the following cancer diagnoses: colorectal 29.5%, breast 29.5%, and liver/biliary tract cancers, 15.9%. Half of the sample had advanced-stage disease. Spouses (70.5%) or adult children (20.4%) were the primary caregivers, with perceived bonding rated as fair (31.8%) or good (65.9%). Rejection of the K-AD was mainly due to the difficulty involved in deciding on EoL care (50%). Comfort while dying was the most common theme expressed by patients (73.8%) and caregivers (66.7%). In terms of treatment directives, dyads advocated for hospice care (66.7%) and reduced support for aggressive treatments of CPR or artificial ventilation. The use of CPR (kappa = 0.43, p = 0.004) and artificial ventilation (kappa = 0.28, p = 0.046) showed significantly mild to moderate concordance among the dyads. Some 16 of the 21 dyads identified their spouses as a proxy, with others designating their adult children. SIGNIFICANCE OF RESULTS: The degree of patient-caregiver concordance on the K-AD seemed applicable, and achieved mild to moderate concordance. Our findings are exploratory but suggest the need for EoL discussions where patient-caregiver dyads are encouraged to participate in EoL care decision making.


The objective of this study is to determine if pediatric advance care planning (pACP) increases adolescent/family congruence in end-of-life (EOL) treatment preferences longitudinally. Adolescents aged 14-21 years with HIV/AIDS and their families were randomized (N = 105 dyads) to three-60-minute sessions scheduled one week apart: either the pACP intervention (survey administered independently, facilitated conversation with adolescent and family present, completion of legal advance directive
document with adolescent and family present) or an active control (developmental history, safety tips, nutrition and exercise education). This longitudinal, single-blinded, multi-site, randomized controlled trial was conducted in six pediatric hospital-based HIV-clinics, located in high HIV mortality cities. The Statement of Treatment Preferences measured adolescent/family congruence in EOL treatment preferences at immediately following the facilitated pACP conversation (Session 2), and at 3-month post-intervention. The mean age of adolescent participants was 18 years (range 14-21 years); 54% were male; and 93% were African-American. One-third had an AIDS diagnosis. Immediately post-intervention the Prevalence Adjusted Bias Adjusted Kappa showed substantial treatment preference agreement for pACP dyads compared to controls (High burden/low chance of survival, PABAK = 0.688 vs. 0.335; Functional impairment, PABAK = 0.687 vs. PABAK= 0.34; Mental impairment, PABKA = 0.717 vs. 0.341). Agreement to limit treatments was greater among intervention dyads than controls (High burden: 14.6% vs. 0%; Functional impairment = 22.9% vs. 4.4%; and Mental impairment: 12.5% vs. 4.4%). Overall treatment preference agreement among pACP dyads was high immediately post-intervention, but decreased over time. In contrast, treatment agreement among control dyads was low and remained low over time. As goals of care change over time with real experiences, additional pACP conversations are needed.


OBJECTIVE: To define the mortality and long-term outcomes of children undergoing tracheostomy. DESIGN: Retrospective chart and Texas Department of Health Bureau of Vital Statistics review of patients admitted to a Pediatric Intensive Care Unit who underwent a tracheostomy between 2001 and 2011. Mortality and decannulation rates were compared based on tracheostomy indication and age. SUBJECTS: A total of 426 patients admitted to a Pediatric Intensive Care Unit in a large tertiary children’s hospital. RESULTS: The median patient age was 1.5 years (3 days-24 years). Primary indications for tracheostomy included (a) airway obstruction, (b) congenital neurologic disease, (c) acquired neurologic disease, (d) congenital respiratory disease, and (e) acquired respiratory disease. Overall, 98 patients (23%) died during the study period, and 75th percentile survival time was 5.9 years (95%CI: 3-8). Patients undergoing a tracheostomy for airway obstruction were the least likely to die; while patients with acquired neurologic disease were most likely to die. A total of 163 patients (38%) were decannulated, and 50% were decannulated at 1.2 years (95%CI: 0.9-1.5). Patients with congenital neurologic disease were the least likely to undergo decannulation. Over half of the patients were discharged from the hospital requiring some form of mechanical respiratory support in addition to their tracheostomy. CONCLUSIONS: In this largest cohort of long-term follow-up to date, we have shown the overall risk of mortality varied according to the indication for the tracheostomy. We were unable to determine exact causes of death. The likelihood of being decannulated also correlates with the underlying indication for the tracheostomy. Pediatr Pulmonol. 2017; 52:946-953. (c) 2017 Wiley Periodicals, Inc.


BACKGROUND: The number of children and young people (CYP) living with life-limiting and life-threatening conditions is rising. Paediatric palliative care is a relatively new aspect of healthcare, the delivery of which is variable, with a wide range of healthcare and voluntary sector providers involved. Policy recommendations are for Specialist Paediatric Palliative Care (SPPC) services to be supported by a physician with specialist training. AIM: To examine the research evidence regarding the distinct benefits of SPPC services, with ‘Specialist Paediatric Palliative Care’ defined as palliative care services supported by a specialist physician. METHOD: Systematic review of studies of SPPC services published in English from 1980 to 2016. Keyword searches were carried out in medical databases (Cochrane, PubMed,
EMBASE, CINAHL and AMED) and a narrative synthesis. RESULTS: Eight studies were identified, most of which were retrospective surveys undertaken within single institutions; three were surveys of bereaved parents and three were medical notes reviews. Together they represented a heterogeneous body of low-level evidence. Cross-cutting themes suggest that SPPC services improve the quality of life and symptom control and can impact positively on place of care and family support. CONCLUSIONS: Current evidence indicates that SPPC services contribute beneficially to the care and experience of CYP and their families, but is limited in terms of quantity, methodological rigour and generalisability. Further research is necessary given the significant workforce and resource implications associated with policy recommendations about the future provision of SPPC and to address the need for evidence to inform the design and delivery of SPPC services.


PURPOSE: Gastrojejunostomy tubes (GJTs) enable enteral nutrition in infants/children with feeding intolerance. However, complications may be increased in small infants. We evaluated our single-institution GJT complication rate and systematically reviewed existing literature. METHODS: With REB approval, a retrospective single-institution analysis of GJT placements between 2009 and 2015 was performed. For the systematic review, MOOSE guidelines were followed. RESULTS: At our institution, 48 children underwent 154/159 successful insertions primarily for gastroesophageal reflux (n=27; 55%) and aspiration (n=11; 23%). Median age at first GJT insertion was 2.2 years (0.2-18). Thirty-five (73%) had an index insertion when <=10kg. GJTs caused 2 perforations and 1 death. The systematic review assessed 48 articles representing 2726 procedures. Overall perforation rate was estimated as 2.1% (n=36 studies, 23/1092, 95% CI: 1.0-3.2). Perforation rates in children <10kg versus >=10kg were estimated as 3.1%/procedure (95% CI: 1.1%-5.0%) and 0.1%/procedure (95% CI: 0%-0.3%), respectively. The relative risk of perforation was 9.4 (95% CI: 2.8-31.3). Overall mortality was estimated as 0.9%/patient (n=39 studies; 95% CI: 0.2-1.6%). Most perforations (19/23; 83%) occurred <=30 days of attempted tube placement. CONCLUSION: Gastrojejunostomy tubes are associated with significant complications and frequently require revision/replacement. Insertion in patients <10kg is associated with increased perforation risk. Caution is warranted in this subgroup. LEVEL OF EVIDENCE: Level II.


Over the last few decades, the fields of fetal surgery and maternal-fetal medicine have developed interventions aimed at modifying severe diseases in utero. Innovations in fetal approaches to congenital diaphragmatic hernia and myelomeningocele have shown considerable promise in modifying the clinical course with fetal intervention. Patients who present to fetal centers to be evaluated for these interventions face challenging decisions that directly relate to questions of mortality and quality of life. This article explores how clinicians might apply the tools and principles of fetal palliative care to supporting a woman and her family who are considering fetal surgery.


Non-cystic fibrosis bronchiectasis (NCFB) has gained renewed interest, due to its increasing health-care burden. Annual mortality statistics in England and Wales showed that under 1,000 people die from bronchiectasis each year, and this number is increasing by 3% yearly. Unfortunately, there is a severe lack of well-powered, randomized controlled trials to guide clinicians how to manage NCFB effectively. Quality-of-life (QOL) measures in NCFB are an important aspect of clinical care that has not been studied well. Commonly used disease-specific questionnaires in children with NCFB are the St George’s

Spinal fusion for idiopathic scoliosis is one of the most painful surgeries experienced by adolescents. Music therapy, utilizing music-assisted relaxation with controlled breathing and imagery, is a promising intervention for reducing pain and anxiety for these patients. It can be challenging to teach new coping strategies to post-operative patients who are already in pain. This study evaluated the effects of introducing music-assisted relaxation training to adolescents before surgery. Outcome measures were self-reported pain and anxiety, recorded on 0-10 numeric rating scale, and observed behavioral indicators of pain and relaxation. The training intervention was a 12-minute video about music-assisted relaxation with opportunities to practice before surgery. Forty-four participants between the ages of 10 and 19 were enrolled. Participants were randomly assigned to the experimental group that watched the video at the preoperative visit or to the control group that did not watch the video. All subjects received a music therapy session with a board certified music therapist on post-operative day 2 while out of bed for the first time. Pain and anxiety were significantly reduced from immediately pre-therapy to post-therapy (paired t-test; p).


OBJECTIVES: To present our single-center’s experience with three palliative critical care transports home from the PICU for terminal extubation. DESIGN: We performed a retrospective chart review of patients transported between January 1, 2012, and December 31, 2014. SETTING: All cases were identified from our institutional pediatric transport database. PATIENTS: Patients were terminally ill children unable to separate from mechanical ventilation in the PICU, who were transported home for terminal extubation and end-of-life care according to their families’ wishes. INTERVENTIONS: Patients underwent palliative care transport home for terminal extubation. MEASUREMENTS AND MAIN RESULTS: The rate of palliative care transports home for terminal extubation during the study period was 2.6 per 100 deaths. The patients were 7 months, 6 years, and 18 years old and had complex chronic conditions. The transfer process was protocolized. The families were approached by the PICU staff during multidisciplinary goals-of-care meetings. Parental expectations were clarified, and home hospice care was arranged pretransfer. All transports were performed by our pediatric critical care transport team, and all terminal extubations were performed by physicians. All patients had unstable medical conditions and urgent needs for transport to comply with the families’ wishes for withdrawal of life support and death at home. As such, all three cases presented similar logistic challenges, including establishing do-not-resuscitate status pretransport, having limited time to organize the transport, and coordinating home palliative care services with available community resources. CONCLUSIONS: Although a relatively infrequent practice in pediatric critical care, transport home for terminal extubation represents a feasible alternative for families seeking out-of-hospital end-of-life care for their critically ill
technology-dependent children. Our single-center experience supports the need for development of formal programs for end-of-life critical care transports to include patient screening tools, palliative care home discharge algorithms, transport protocols, and resource utilization and cost analyses.


BACKGROUND: Evidence supports music-based oncologic support interventions including music therapy. By comparison, little is understood about music-based self-care. This meta-ethnography examined five published qualitative studies to extend understanding of music's relevance, including helpfulness, for people affected by cancer; including children, adolescents, and adults with cancer, carers, and the bereaved. OBJECTIVE: To improve understanding of music's broad relevance for those affected by cancer. METHODS: Meta-ethnography strategies informed the analysis. Five studies were synthesized that included 138 participants: 26 children and 28 parents of children with cancer; 12 adolescents and young adults with cancer; 52 adults with cancer; 12 carers; and 8 bereaved. Studies' category and thematic findings were compared and integrated into third-order interpretations, and a line of argument. Perspectives from the five studies that illuminated the line of argument were developed. RESULTS: Music usage can remain incidental, continue normally, and/or change because of cancer's harsh effects. Music can be a lifeline, support biopsychosocial and spiritual well-being, or become elusive, that is, difficult to experience. Music helps or intrudes because it extends self-awareness and social connections, and prompts play, memories, imageries, and legacies. Music therapists may help patients and carers to recover or extend music's helpful effects. CONCLUSIONS: Cancer care can be improved through offering music-based resources/services, which give cancer patients and carers opportunities to extend music usage for personal support and, for carers, to support patients. Music therapists can advocate for such resources and educate health professionals about assessing/recognizing when patients' and carers' changed music behaviors signify additional support needs.


Chronic suppurative lung disease (CSLD) and bronchiectasis in children and adolescents are important causes of respiratory morbidity and reduced quality of life (QoL), also leading to subsequent premature death during adulthood. Acute respiratory exacerbations in pediatric CSLD and bronchiectasis are important markers of disease control clinically, given that they impact upon QoL and increase health-care-associated costs and can adversely affect future lung functioning. Preventing exacerbations in this population is, therefore, likely to have significant individual, familial, societal, and health-sector benefits. In this review, we focus on therapeutic interventions, such as drugs (antibiotics, mucolytics, hyperosmolar agents, bronchodilators, corticosteroids, non-steroidal anti-inflammatory agents), vaccines and physiotherapy, and care-planning, such as post-hospitalization management and health promotion strategies, including exercise, diet, and reducing exposure to environmental toxicants. The review identified a conspicuous lack of moderate or high-quality evidence for preventing respiratory exacerbations in children and adolescents with CSLD or bronchiectasis. Given the short- and long-term impact of exacerbations upon individuals, their families, and society as a whole, large studies addressing interventions at the primary and tertiary prevention phases are required. This research must include children and adolescents in both developing and developed countries and address long-term health outcomes.

BACKGROUND: The aim of this study was to determine how end-of-life decisions (EOLD) on limitations of life-sustaining treatment (LST) are made in three different types of intensive care units (ICUs) in Slovenia. METHODS: A national multicenter prospective study among 31 adult and three pediatric/neonatal ICUs (PICUs). The questionnaire form on EOLD was designed to assess the clinical practice. Data were collected between January 1, 2013, and March 31, 2013. For statistical analysis we used IBM(R) SPSS(R) Statistics 20 software package. RESULTS: Overall, 4226 patients were admitted to ICUs, the EOLD on limitation of LST were performed in 112 patients (23.9%) out of 468 patients, which had died and/or had been subject to EOLD on limitation of LST. In 86.2% of the cases, patients had impaired competence. Advance directives were available only in 1.9% (2 out of 106 patients) of the cases. In the majority of cases, the EOLD was taken by the physicians (96.2%). In 61.8% of the cases, patient representatives were involved in the discussion about limitation of LST. The do-not-resuscitate order and withholding of inotropes/vasopressors were the most common measures to limit LST. Most commonly withdrawn were inotropes/vasopressors and antibiotics. Palliative care was included in 72.3% of the cases (80 out of 112 patients), however, palliative care team was only included in 4% of the cases. CONCLUSIONS: No differences were found between the three different types of ICUs in EOLD on limitation of LST even though limitation of LST was provided regularly. The most commonly limited LST measures include mechanical ventilation, inotropes/vasopressors, hemodialysis, and antibiotics. Almost none of the patients had advance directives in place. Palliative care team was available in only few cases.


OBJECTIVE: We previously developed the paper-based Symptom Screening in Pediatrics Tool (SSPedi) designed for paediatric cancer symptom screening. Objectives were to evaluate and refine the electronic mobile application (app) of SSPedi using the opinions of children with cancer. METHODS: Participants were children 8-18 years of age with cancer. Participants completed electronic SSPedi on their own and then responded to semistructured questions to determine whether they found electronic SSPedi easy or difficult to complete and understand, understood and liked the app features (audio and animation), and understood previously difficult to understand concepts with the introduction of a help menu. After each group of 10 children, responses were reviewed to determine whether modifications were required. RESULTS: 20 children evaluated electronic SSPedi. None found electronic SSPedi difficult to complete or understand. All children understood the app features and each of the 4 more difficult to understand concepts after using the help menu. 19 of 20 children thought the app was a good way to communicate with doctors and nurses. CONCLUSIONS: We finalised an electronic version of SSPedi that is easy to use and understand with features specifically designed to facilitate child self-report. Future work will evaluate the psychometric properties of electronic SSPedi.


The optimal treatment for medically refractory epilepsy in Aicardi syndrome (AS) is still unclear. Palliative surgical treatment, including vagus nerve stimulation and corpus callosotomy, has therefore been used. There is limited data on the role of resective epilepsy surgery as a treatment choice in patients with AS. Here, we describe the seizures, anatomo-pathological findings, and neurodevelopmental outcome of palliative epilepsy surgery in two children with AS who had resective epilepsy surgery at the Cleveland
Clinic. The related literature is also reviewed. Case 1 had a left functional hemispherectomy and was free of seizures and hypsarrhythmia for six months after surgery. Her gross motor skills improved after surgery. Outcome at 43 months was 1-3 isolated spasms per day. Case 2 had a right fronto-parietal lobectomy. Her seizures improved in frequency and severity, but remained daily after epilepsy surgery. Neurodevelopment changes included improved alertness and recognition of caregivers. This patient died 21 months after epilepsy surgery of unclear causes. Surgical pathology in both cases showed focal cortical dysplasia associated with other findings, such as nodular heterotopia and polymicrogyria. Epilepsy surgery could be an alternative palliative treatment choice in selective cases of AS, but studies on a larger patient cohort are needed to identify the possible role of surgery in children with AS. The complexity of the pathological findings may offer an explanation for the severity of seizures in AS.  


AIM: Parent-reporting is needed to examine Quality of Life (QoL) of children with cerebral palsy (CP) across all severities. This study examines whether QoL changes between childhood and adolescence, and what predicts adolescent QoL. METHOD: SPARCLE is a European cohort study of children with CP, randomly sampled from population databases. Of 818 8-12-year-olds joining the study, 594 (73%) were revisited as 13-17-year-olds. The subject of this report is the 551 (316 boys, 235 girls) where the same parent reported QoL on both occasions using KIDSCREEN-52 (transformed Rasch scale, mean 50, SD 10 per domain). Associations were assessed using linear regression. RESULTS: Between childhood and adolescence, average QoL reduced in six domains (1.3-3.8 points, p<0.01) and was stable in three (Physical wellbeing, Autonomy, Social acceptance). Socio-demographic factors had little predictive value. Childhood QoL was a strong predictor of all domains of adolescent QoL. Severe impairments of motor function, IQ or communication predicted higher adolescent QoL on some domains; except that severe motor impairment predicted lower adolescent QoL on the Autonomy domain. More psychological problems and higher parenting stress in childhood and their worsening by adolescence predicted lower QoL in five and eight domains respectively; contemporaneous pain in seven domains. The final model explained 30%-40% of variance in QoL, depending on domain. INTERPRETATION: In general, impairment severity and socio-demographic factors were not predictors of lower adolescent QoL. However, pain, psychological problems and parenting stress were predictors of lower adolescent QoL in most domains. These are modifiable factors and addressing them may improve adolescent QoL.  


BACKGROUND: Adolescent and young adult oncology (AYAO) patients often receive intensive medical care and experience significant symptoms at the end of life (EOL). OBJECTIVE: This study aimed to describe the characteristics of AYAO patients aged 15-26 years who died as inpatients in a hospital and to compare the illness and EOL experiences of AYAO patients who did and did not receive palliative care (PC). DESIGN AND SETTING: A standardized data extraction tool was used to collect information about demographics, treatment, terminal characteristics, and symptoms during the last month of life (LMOL) for 69 AYAO patients who died while hospitalized between 2008 and 2014. MEASUREMENTS AND RESULTS: AYAO patients who died in the hospital required considerable medical and psychosocial care and experienced numerous symptoms during the LMOL. Compared to those patients who received no formal PC services, patients followed by the PC team were less likely to die in the intensive care unit (ICU) (38% vs. 68%, p = 0.024) and less likely to have been on a ventilator (34% vs. 63%, p = 0.028) during the LMOL. They also received fewer invasive medical procedures during the LMOL (median, 1 vs. 3 procedures, p = 0.009) and had a do not resuscitate order in place for a longer time before death (median, 6 vs. two days, p = 0.008). CONCLUSIONS: Involvement of the PC team was associated with the receipt of less intensive treatments and fewer deaths in the ICU.

PURPOSE: Cancer is the leading cause of nonaccidental deaths among adolescents and young adults (AYAs). In Denmark, there are substantial gaps in knowledge concerning how AYAs with cancer perceive their diagnostic and therapeutic trajectory and report health-related outcomes. The aim of this study is to describe the development of a questionnaire targeting AYAs with cancer aiming to evaluate treatment and survivorship from the perspective of the patients. METHODS: Identification of themes and development of items included in the questionnaire were based on a synthesis of literature and qualitative interviews with AYAs in an iterative process involving both a professional advisory panel and a youth panel. During the development process, items were validated through cognitive interviews. RESULTS: The final questionnaire contained 151 closed- and open-ended items divided into 6 sections regarding: (1) "Time before treatment," (2) "Being told about your illness," (3) "Being a young patient," (4) "Your treatment," (5) "Receiving help living with and after Cancer," and (6) "How are you feeling today?." One hundred one items were specifically developed for this study, while 50 were standardized validated indexes. The questionnaire combined different types of items such as needs, preferences, experiences, and patient-reported outcomes. CONCLUSION: This is one of few developed questionnaires aiming to evaluate the perspective of AYAs with cancer through their whole cancer trajectory. Results from the questionnaire survey are intended for quality improvements and research in AYA cancer care. The study highlights the importance of an extensive patient involvement in all steps of a questionnaire development process.


BACKGROUND AND OBJECTIVES: Gastroesophageal reflux (GER), aspiration, and secondary complications lead to morbidity and mortality in children with neurologic impairment (NI), dysphagia, and gastrostomy feeding. Fundoplication and gastrojejunal (GJ) feeding can reduce risk. We compared GJ to fundoplication using first-year postprocedure reflux-related hospitalization (RRH) rates. METHODS: We identified children with NI, dysphagia requiring gastrostomy tube feeding and GER undergoing initial GJ placement or fundoplication from January 1, 2007 to December 31, 2012. Data came from the Pediatric Health Information Systems augmented by laboratory, microbiology, and radiology results. GJ placement was ascertained using radiology results and fundoplication by International Classification of Diseases, Ninth Revision, Clinical Modification codes. Subjects were matched within hospital using propensity scores. The primary outcome was first-year postprocedure RRH rate (hospitalization for GER disease, other esophagitis, aspiration pneumonia, other pneumonia, asthma, or mechanical ventilation). Secondary outcomes included failure to thrive, death, repeated initial intervention, crossover intervention, and procedural complications. RESULTS: We identified 1178 children with fundoplication and 163 with GJ placement, matching 114 per group. Matched sample RRH incident rate per child-year (95% confidence interval) for GJ was 2.07 (1.62-2.64) and for fundoplication 1.67 (1.28-2.18), P = .19. Odds of death were similar between groups. Failure to thrive, repeat of initial intervention, and crossover intervention were more common in the GJ group. CONCLUSIONS: In children with NI, GER, and dysphagia: fundoplication and GJ feeding have similar RRH outcomes. Either intervention can reduce future aspiration risk; the choice can reflect non-RRH-related complication risks, caregiver preference, and clinician recommendation.

There are few reports on the prognosis of prenatally diagnosed trisomy 13 in relation to postnatal management. The aim of this study was to report on the prenatal and postnatal outcomes and postnatal management of trisomy 13 fetuses that were prenatally diagnosed at our center between 2003 and 2015. The data were retrospectively reviewed from medical records. Of the 31 cases of trisomy 13, 12 patients were diagnosed before 22 weeks of gestation, and 19 were diagnosed at or after 22 weeks of gestation. Nine families opted for termination of the pregnancy, 14 fetuses died, and 8 were born alive. Aggressive treatment was requested in two of the live births, with one patient achieving long-term survival (7 years). The other died during infancy (Day 61). One out of four who received palliative treatment is alive at two years of age with only nutrition supplementation. These three patients who achieved neonatal survival had few structural anomalies. Fetal death and early neonatal death are common in trisomy 13; however, fetuses that receive medical treatment for cases without major ultrasound abnormalities may achieve neonatal survival. Therefore, it is useful to provide comprehensive information, including precise ultrasound findings and treatment options, to parents with trisomy 13 fetuses during genetic counseling.


OBJECTIVE: Caregivers of cancer patients face intense demands throughout the course of the disease, survivorship, and bereavement. Caregiver burden, needs, satisfaction, quality of life, and other significant areas of caregiving are not monitored regularly in the clinic setting, resulting in a need to address the availability and clinical effectiveness of cancer caregiver distress tools. This review aimed to determine the availability of cancer caregiver instruments, the variation of instruments between different domains of distress, and that between adult and pediatric cancer patient populations. METHOD: A literature search was conducted using various databases from 1937 to 2013. Original articles on instruments were extracted separately if not included in the original literature search. The instruments were divided into different areas of caregiver distress and into adult versus pediatric populations. Psychometric data were also evaluated. RESULTS: A total of 5,541 articles were reviewed, and 135 articles (2.4%) were accepted based on our inclusion criteria. Some 59 instruments were identified, which fell into the following categories: burden (n = 26, 44%); satisfaction with healthcare delivery (n = 5, 8.5%); needs (n = 14, 23.7%); quality of life (n = 9, 15.3%); and other issues (n = 5, 8.5%). The median number of items was 29 (4-125): 20/59 instruments (33.9%) had <=20 items; 13 (22%) had <=20 items and were psychometrically sound, with 12 of these 13 (92.3%) being self-report questionnaires. There were 44 instruments (74.6%) that measured caregiver distress for adult cancer patients and 15 (25.4%) for caregivers of pediatric patients. SIGNIFICANCE OF RESULTS: There is a significant number of cancer caregiver instruments that are self-reported, concise, and psychometrically sound, which makes them attractive for further research into their clinical use, outcomes, and effectiveness.


PURPOSE: There is a paucity of effective long-term medication treatment for secondary dystonias. In situations where significantly impairing secondary dystonias fail to respond to typical enteral medications and intrathecal (or even intraventricular) baclofen, consideration should be given to the use of deep brain stimulation (DBS). While Level I evidence and long-term follow-up clearly demonstrate the efficacy of DBS for primary dystonia, the evidence for secondary dystonia remains mixed and unclear. In this study,
we report our experience with pediatric subjects who have undergone DBS for secondary dystonia. METHODS: We discuss the indications and outcomes of DBS procedures completed at our center. We also present a detailed discussion of the considerations in the management of these patients as well as a literature review. RESULTS: Of the four cases retrospectively examined here, all subjects experienced reductions in the severity of their dystonia (ranging from 0 to 100% on both the Barry-Albright Dystonia (BAD) and Burke-Fahn-Marsden Dystonia Rating Scale-Motor (BFMDRS-M) scales). CONCLUSIONS: Pallidal DBS should be considered among children with functionally debilitating, medication-resistant secondary dystonia. Patients without fixed skeletal deformities who have experienced a short duration of symptoms are most likely to benefit from this intervention.


BACKGROUND: There are few published data to guide the use and timing of palliative radiation therapy (RT) in children. We aimed to determine the clinical outcomes of palliative RT in children and the relationship with palliative care and hospice referrals. PROCEDURE: A retrospective chart review was performed on all patients younger than 18 years who received palliative RT in our clinic from January 2005 to January 2015. RESULTS: In the specified time period, 50 children underwent 83 courses of palliative RT. Median survival after treatment was 124 days (range, 1-1141 days). Fifteen courses were delivered to children in the last 30 days of life (dol). Palliative RT was successful in 89% of courses delivered before the last 30 dol versus 28% of courses delivered in the last 30 dol (p < 0.0001, Fisher's exact test). At the time of data collection, 43 children were deceased. Altogether, 88% of children who received palliative RT were also referred to our institution’s pediatric palliative care team or to hospice at some time in their course. Of the children who died, 74% were referred to hospice and 34% were on hospice while receiving palliative RT. For children not already on hospice, the median time to hospice referral was 96 days after the last fraction (range, 0-924 days). CONCLUSIONS: Palliative RT is effective in children with advanced cancer, although less so in the last 30 dol. With careful care coordination and multidisciplinary collaboration, RT can be successfully integrated into supportive and end-of-life care for children with advanced cancer.


Gastrointestinal dysmotility is common in children and young people with neurodisabling conditions. In this article we seek to highlight the increasing difficulties faced by paediatricians in managing intestinal failure in this patient group. It is becoming clear that, as the median age for survival increases, intestinal failure is a significant problem, and can in some cases become life-limiting. The ethical issues around starting children with life-limiting conditions on parenteral nutrition (PN) are extremely complicated, not least because we are ignorant of the mechanism of intestinal failure in these children, and indeed, which of these children might be able to return to enteral feeding after a period of PN. Our article highlights these issues, drawing on our experience of a particularly difficult case, which we hope will stimulate further discussion among paediatricians providing care for children with neurodisabling conditions.


BACKGROUND: Population-based research to identify underserviced populations and the impact of palliative care (PC) is limited as the validity of such data to identify PC services is largely unknown. OBJECTIVE: To determine the validity of using such data to identify the involvement of specialized pediatric PC teams among children with cancer. DESIGN: Retrospective cohort. SUBJECTS: Ontario children with cancer who died between 2000 and 2012, received care through a pediatric institution with a specialized PC team and a clinical PC database. MEASUREMENTS: All patients in the clinical databases were linked to population-based health services administrative databases. Six algorithms were created to indicate the use of formal pediatric PC teams based on the record type (physician billings vs. inpatient records vs. both) and number of eligible codes required (>/=1 vs. >/=2). Each was validated against the pediatric PC clinical databases. RESULTS: The cohort comprised 572 children; 243 were in the clinical databases. Algorithms using only inpatient records had high specificity (80%-95%) but poor sensitivity (21%-56%). Including physician billings increased sensitivity but lowered specificity. The algorithm with overall best performance required >/=2 physician billing or inpatient diagnosis codes indicating PC [sensitivity 0.79 (95% CI 0.73-0.84), specificity 0.58 (95% CI 0.53-0.64)]. CONCLUSIONS: Health administrative data identifies involvement of specialized pediatric PC teams with good sensitivity but low specificity. Studies using such data alone to compare patients receiving and not receiving specialized pediatric PC are at significant risk of misclassification and potential bias. Population-based PC databases should be established to conduct rigorous population-based PC research. https://www.ncbi.nlm.nih.gov/pubmed/27836825


OBJECTIVE: To identify which quality indicators (QI) predict patient satisfaction. METHODS: A cross-sectional design using a validated tool was administered using a Web-based platform. Parents (n = 405) who experienced a life-limiting fetal diagnosis and opted to continue their pregnancy provided feedback on 37 QI and satisfaction with prenatal care. Descriptive analyses and logistic regression identified relationships among variables. RESULTS: Parental satisfaction with care was 75.6%. Statistically significant differences in mean scores were reported with satisfied patients reporting higher agreement with quality indicators. Parents who were satisfied with their care had 1.9 times the odds of reporting that consistent care was provided (CI: 1.4-2.4, p < 0.01), 1.8 times the odds of reporting compassionate care (CI: 1.4-2.5, p < 0.01) and 1.8 times the odds that they received help to cope with their emotions (CI: 1.4-2.3, p < 0.01). The model correctly predicted parent satisfaction 92% of the time. CONCLUSION: Provision of consistent prenatal care is an important quality indicator for this population of parents. The odds of securing satisfied parents increase when families are treated with compassion and given resources to help them cope with the emotionally devastating experiences associated with a life-limiting fetal diagnosis. https://www.ncbi.nlm.nih.gov/pubmed/27238629


BACKGROUND: Out-of-hospital cardiac arrest (OHCA) is a major cause of death worldwide. Cardiac arrest can be subdivided into asphyxial and non asphyxial etiologies. An asphyxia arrest is caused by lack of oxygen in the blood and occurs in drowning and choking victims and in other circumstances. A non asphyxial arrest is usually a loss of functioning cardiac electrical activity. Cardiopulmonary resuscitation (CPR) is a well-established treatment for cardiac arrest. Conventional CPR includes both chest compressions and ‘rescue breathing’ such as mouth-to-mouth breathing. Rescue breathing is delivered between chest compressions using a fixed ratio, such as two breaths to 30 compressions or can be delivered asynchronously without interrupting chest compression. Studies show that applying continuous chest compressions is critical for survival and interrupting them for rescue breathing might increase risk of death. Continuous chest compression CPR may be performed with or without rescue breathing. OBJECTIVES: To assess the effects of continuous chest compression CPR (with or without
rescue breathing) versus conventional CPR plus rescue breathing (interrupted chest compression with pauses for breaths) of non-asphyxial OHCA. SEARCH METHODS: We searched the Cochrane Central Register of Controlled Trials (CENTRAL; Issue 1 2017); MEDLINE (Ovid) (from 1985 to February 2017); Embase (1985 to February 2017); Web of Science (1985 to February 2017). We searched ongoing trials databases including controlledtrials.com and clinicaltrials.gov. We did not impose any language or publication restrictions. SELECTION CRITERIA: We included randomized and quasi-randomized studies in adults and children suffering non-asphyxial OHCA due to any cause. Studies compared the effects of continuous chest compression CPR (with or without rescue breathing) with interrupted CPR plus rescue breathing provided by rescuers (bystanders or professional CPR providers). DATA COLLECTION AND ANALYSIS: Two authors extracted the data and summarized the effects as risk ratios (RRs), adjusted risk differences (ARDs) or mean differences (MDs). We assessed the quality of evidence using GRADE. MAIN RESULTS: We included three randomized controlled trials (RCTs) and one cluster-RCT (with a total of 26,742 participants analysed). We identified one ongoing study. While predominantly adult patients, one study included children. Untrained bystander-administered CPRThree studies assessed CPR provided by untrained bystanders in urban areas of the USA, Sweden and the UK. Bystanders administered CPR under telephone instruction from emergency services. There was an unclear risk of selection bias in two trials and low risk of detection, attrition, and reporting bias in all three trials. Survival outcomes were unlikely to be affected by the unblinded design of the studies.We found high-quality evidence that continuous chest compression CPR without rescue breathing improved participants’ survival to hospital discharge compared with interrupted chest compression with pauses for rescue breathing (ratio 15:2) by 2.4% (14% versus 11.6%; RR 1.21, 95% confidence interval (CI) 1.01 to 1.46; 3 studies, 3031 participants).One trial reported survival to hospital admission, but the number of participants was too low to be certain about the effects of the different treatment strategies on survival to admission(RR 1.18, 95% CI 0.94 to 1.48; 1 study, 520 participants; moderate-quality evidence). There were no data available for survival at one year, quality of life, return of spontaneous circulation or adverse effects. There was insufficient evidence to determine the effect of the different strategies on neurological outcomes at hospital discharge (RR 1.25, 95% CI 0.94 to 1.66; 1 study, 1286 participants; moderate-quality evidence). The proportion of participants categorized as having good or moderate cerebral performance was 11% following treatment with interrupted chest compression plus rescue breathing compared with 10% to 18% for those treated with continuous chest compression CPR without rescue breathing. CPR administered by a trained professional In one trial that assessed OHCA CPR administered by emergency medical service professionals (EMS) 23,711 participants received either continuous chest compression CPR (100/minute) with asynchronous rescue breathing (10/minute) or interrupted chest compression with pauses for rescue breathing (ratio 30:2). The study was at low risk of bias overall. After OHCA, risk of survival to hospital discharge is probably slightly lower for continuous chest compression CPR with asynchronous rescue breathing compared with interrupted chest compression plus rescue breathing (9.0% versus 9.7%) with an adjusted risk difference (ARD) of -0.7%; 95% CI (-1.5% to 0.1%); moderate-quality evidence. There is high-quality evidence that survival to hospital admission is 1.3% lower with continuous chest compression CPR with asynchronous rescue breathing compared with interrupted chest compression plus rescue breathing (24.6% versus 25.9%; ARD -1.3% 95% CI (-2.4% to -0.2%)). Survival at one year and quality of life were not reported. Return of spontaneous circulation is likely to be slightly lower in people treated with continuous chest compression CPR plus asynchronous rescue breathing (24.2% versus 25.3%; -1.1% (95% CI -2.4 to 0.1)), high-quality evidence. There is high-quality evidence of little or no difference in neurological outcome at discharge between these two interventions (7.0% versus 7.7%; ARD -0.6% (95% CI -1.4 to 0.1)). Rates of adverse events were 54.4% in those treated with continuous chest compressions plus asynchronous rescue breathing versus 55.4% in people treated with interrupted chest compression plus rescue breathing compared with the ARD being -1% (-2.3 to 0.4), moderate-quality evidence). AUTHORS’ CONCLUSIONS: Following OHCA, we have found that bystander-administered chest compression-only CPR, supported by telephone instruction, increases the proportion of people who survive to hospital discharge compared with conventional interrupted chest compression CPR plus rescue breathing. Some uncertainty remains about how well neurological function is preserved in this population and there is no information available regarding adverse effects. When CPR was performed by EMS providers, continuous chest compressions plus asynchronous rescue breathing did not result in higher rates for survival to hospital discharge compared to interrupted chest compression plus rescue breathing. The
results indicate slightly lower rates of survival to admission or discharge, favourable neurological outcome and return of spontaneous circulation observed following continuous chest compression. Adverse effects are probably slightly lower with continuous chest compression. Increased availability of automated external defibrillators (AEDs), and AED use in CPR need to be examined, and also whether continuous chest compression CPR is appropriate for paediatric cardiac arrest.

Pain, Symptom Assessment and Relief


A framework for defining pain terms such as acute, persistent, prolonged or chronic pain to newborns was derived from the scientific literature on neonatal pain assessments, previous attempts to define chronic pain and the clinical and neurophysiological features of neonatal pain. This novel framework incorporates the temporal features, localising characteristics, and secondary effects of the pain experienced, as well as the behavioural and physiological response patterns of newborns.

**CONCLUSION:** Although not evidence-based, this framework provides an initial starting point for defining commonly used neonatal pain terms. It will require future revision/refinement based on the accumulating evidence for non-acute pain.


**AIM:** Continuous pain occurs routinely, even after invasive procedures, or inflammation and surgery, but clinical practices associated with assessments of continuous pain remain unknown. **METHODS:** A prospective cohort study in 243 neonatal intensive care units (NICUs) from 18 European countries recorded the frequency of pain assessments, use of mechanical ventilation, sedation, analgesia or neuromuscular blockade for each neonate for up to 28 days after NICU admission. **RESULTS:** Only 2113 of 6648 (31.8%) of neonates received assessments of continuous pain, occurring variably among tracheal ventilation (TrV, 46.0%), noninvasive ventilation (NIV, 35.0%) and no ventilation (NoV, 20.1%) groups (p < 0.001). Daily assessments for continuous pain occurred in only 10.4% of all neonates (TrV: 14.0%, NIV: 10.7%, NoV: 7.6%; p < 0.001). More frequent assessments of continuous pain occurred in NICUs with pain guidelines, nursing champions and surgical admissions (all p < 0.01), and for newborns <32 weeks gestational age, those requiring ventilation, or opioids, sedatives-hypnotics, general anaesthetics (O-SH-GA) (all p < 0.001), or surgery (p = 0.028). Use of O-SH-GA drugs increased the odds for pain assessment in the TrV (OR:1.60, p < 0.001) and NIV groups (OR:1.40, p < 0.001).

**CONCLUSION:** Assessments of continuous pain occurred in less than one-third of NICU admissions and daily in only 10% of neonates. NICU clinical practices should consider including routine assessments of continuous pain in newborns.


Pain is a significant public health problem that affects all populations and has significant financial, physical and psychological impact. Opioid medications, once the mainstay of pain therapy across the spectrum, can be associated with significant morbidity and mortality. Centers for Disease and Control (CDC) guidelines recommend that non-opioid pain medications are preferred for chronic pain outside of certain indications (cancer, palliative and end of life care). Mindfulness, hypnosis, acupuncture and yoga are four examples of mind-body techniques that are often used in the adult population for pain and symptom management. In addition to providing significant pain relief, several studies have reported reduced use of opioid medications when mind-body therapies are implemented. Mind-body medicine is another approach that can be used in children with both acute and chronic pain to improve pain management and quality of life.


Pain management in the neonatal ICU remains challenging for many clinicians and in many complex care circumstances. The authors review general pain management principles and address the use of pain scales, non-pharmacologic management, and various agents that may be useful in general neonatal practice, procedurally, or at the end of life. Chronic pain and neonatal abstinence are also noted. https://www.ncbi.nlm.nih.gov/pubmed/28131321


BACKGROUND: Anxiety is a common form of psychological distress in patients with cancer. One recognized nonpharmacological intervention to reduce anxiety for various populations is hypnotherapy or hypnosis. However, its effect in reducing anxiety in cancer patients has not been systematically evaluated. AIM: This meta-analysis was designed to synthesize the immediate and sustained effects of hypnosis on anxiety of cancer patients and to identify moderators for these hypnosis effects. METHODS: Qualified studies including randomized controlled trials (RCT) and pre-post design studies were identified by searching seven electronic databases: Scopus, Medline Ovidsp, PubMed, PsycINFO-Ovid, Academic Search Premier, CINAHL Plus with FT-EBSCO, and SDOL. Effect size (Hedges' g) was computed for each study. Random-effect modeling was used to combine effect sizes across studies. All statistical analyses were conducted with Comprehensive Meta-Analysis, version 2 (Biostat, Inc., Englewood, NJ, USA). RESULTS: Our meta-analysis of 20 studies found that hypnosis had a significant immediate effect on anxiety in cancer patients (Hedges’ g: 0.70-1.41, p < .01) and the effect was sustained (Hedges’ g: 0.61-2.77, p < .01). The adjusted mean effect size (determined by Duvan and Tweedie’s trim-and-fill method) was 0.46. RCTs had a significantly higher effect size than non-RCT studies. Higher mean effect sizes were also found with pediatric study samples, hematological malignancy, studies on procedure-related stressors, and with mixed-gender samples. Hypnosis delivered by a therapist was significantly more effective than self-hypnosis. LINKING EVIDENCE TO ACTION: Hypnosis can reduce anxiety of cancer patients, especially for pediatric cancer patients who experience procedure-related stress. We recommend therapist-delivered hypnosis should be preferred until more effective self-hypnosis strategies are developed. https://www.ncbi.nlm.nih.gov/pubmed/28267893


Over the past 20 years our knowledge about evidence-based psychological interventions for pediatric chronic pain has dramatically increased. Overall, the evidence in support of psychological interventions for pediatric chronic pain is strong, demonstrating positive psychological and behavioral effects for a variety of children with a range of pain conditions. However, wide scale access to effective psychologically-based pain management treatments remains a challenge for many children who suffer with pain. Increasing access to care and reducing persistent biomedical biases that inhibit attainment of psychological services are a central focus of current pain treatment interventions. Additionally, as the number of evidence-based treatments increase, tailoring treatments to a child or family’s particular needs is increasingly possible. This article will (1) discuss the theoretical frameworks as well as the specific psychological skills and strategies that currently hold promise as effective agents of change; (2) review and summarize trends in the development of well-researched outpatient interventions over the past ten years; and (3) discuss future directions for intervention research on pediatric chronic pain. https://www.ncbi.nlm.nih.gov/pubmed/28165415

Mucopolysaccharidoses (MPSs) are a group of rare, genetic lysosomal storage disorders. They are caused by deficiencies of the lysosomal enzymes involved in the degradation of glycosaminoglycans (GAGs). Pain is a common feature in mucopolysaccharidoses. However, the pathophysiology of pain in this group of diseases is still unclear and genesis of pain is multifactorial. Currently, poor data about pain management in these patients are available. Here, we present our clinical experience in complex pain management in three children with MPS.


CONTEXT: Although patient-controlled analgesia (PCA) is an effective pain control modality, there is a lack of large studies on PCA safety in pediatric patients. OBJECTIVES: This study compared the delivery of morphine either via intravenous route (morphine IV) or via PCA device (morphine PCA) on risk of cardiopulmonary resuscitation (CPR) and mechanical ventilation (MV) using a large administrative database. METHODS: We assembled a retrospective cohort of pediatric inpatients between five and 21 years old in 42 children’s hospitals between 2007 and 2011 from the Pediatric Health Information System database. After propensity score matching, we created matched cohorts of morphine PCA and morphine IV patients, in both surgical and nonsurgical samples, who were similar on demographic, clinical, and hospital-level factors. We examined if PCA administration was associated with greater likelihood of CPR or MV up to two days after drug administration. RESULTS: Surgical and nonsurgical patients administered morphine PCA generally had lower odds of having MV on the baseline day and up to two days after PCA exposure, although these estimates were not statistically significant. Similarly, PCA exposure was associated with about 20%-44% lower odds of same day CPR in both surgical and nonsurgical patients, with a slightly greater reduction in the odds of CPR in the surgical patients. CONCLUSION: In this large pediatric inpatient population, morphine administered via PCA device for surgical and nonsurgical pain was not associated with an increased risk of receiving CPR or MV, and was associated with slightly better safety outcomes than intravenous morphine.


OBJECTIVES: Assessment and management of symptoms exhibited by infants can be challenging, especially at the end-of-life, because of immature physiology, non-verbal status, and limited symptoms assessment tools for staff nurses to utilize. This study explored how nurses observed and managed infant symptoms at the end-of-life in a neonatal intensive care unit. METHODOLOGY/DESIGN/METHODS: This was a qualitative, exploratory study utilizing semi-structured face-to-face interviews, which were tape-recorded, transcribed verbatim, and then analyzed using the Framework Approach. SETTING: The sample included 14 staff nurses who cared for 20 infants who died at a large children’s hospital in the Midwestern United States. MAIN OUTCOME MEASURES: Nurses had difficulty recalling and identifying infant symptoms. Barriers to symptom identification were discovered based on the nursing tasks associated with the level of care provided. RESULTS: Three core concepts emerged from analyses of the transcripts: Uncertainty, Discomfort, and Chaos. Nurses struggled with difficulties related to infant prognosis, time of transition to end-of-life care, symptom recognition and treatment, lack of knowledge related to various cultural and religious customs, and limited formal end-of-life education. CONCLUSION: Continued research is needed to improve symptom assessment of infants and increase nurse comfort with the provision of end-of-life care in the neonatal intensive care unit.


Dr Stefan Friedrichsdorf speaks to Commissioning Editor Jade Parker: Stefan Friedrichsdorf, MD, is medical director of the Department of Pain Medicine, Palliative Care and Integrative Medicine at Children's Hospitals and Clinics of Minnesota in Minneapolis/St Paul, MN, USA, home to one of the largest and most comprehensive programs of its kind in the country. The pain and palliative care program is devoted to control acute, chronic/complex and procedural pain for inpatients and outpatients in close collaboration with all pediatric subspecialties at Children's Minnesota. The team also provides holistic, interdisciplinary care for children and teens with life limiting or terminal diseases and their families. Integrative medicine provides and teaches integrative, nonpharmacological therapies (such as massage, acupuncture/acupressure, biofeedback, aromatherapy and self-hypnosis) to provide care that promotes optimal health and supports the highest level of functioning in all individual children's activities. In this second part of the interview they discuss multimodal (opioid-sparing) analgesia for hospitalized children in pain and how analgesics and adjuvant medications, interventions, rehabilitation, psychological and integrative therapies act synergistically for more effective pediatric pain control with fewer side effects than a single analgesic or modality.


Dr Stefan Friedrichsdorf speaks to Jade Parker, Commissioning Editor: Stefan J Friedrichsdorf, MD, is medical director of the Department of Pain Medicine, Palliative Care and Integrative Medicine at Children’s Hospitals and Clinics of Minnesota, Minneapolis/St Paul, MN, USA, home to one of the largest and most comprehensive programs of its kind in the country. The interdisciplinary pain team is devoted to prevent and treat acute, procedural, neuropathic, psycho-social-spiritual, visceral, and chronic/complex pain for all inpatients and outpatients in close collaboration with all pediatric subspecialties at Children's Minnesota. The palliative care team also provides holistic care for pediatric patients with life-threatening diseases and adds an extra layer of support to the care of children with serious illness and their families. Integrative medicine provides and teaches integrative ('non-pharmacological') therapies, such as massage, acupuncture/acupressure, biofeedback, aromatherapy and self-hypnosis, to provide care that promotes optimal health and supports the highest level of functioning in all individual children’s activities. Children’s Minnesota became the first children’s hospital to system-wide implement a "Children's Comfort Promise: We promise to do everything to prevent and treat pain," resulting in decrease or elimination of needle pain caused by vaccinations, blood draws, intravenous access, and injections in more than 200,000 children annually.


Respite workers (RW) commonly care for children with intellectual disabilities (ID), and pain is common for these children. Little is known about factors which inform RW pain assessment and management-related decisions. OBJECTIVES: To describe/determine the following in response to a series of pain-related scenarios (e.g., headache, falling): (1) factors considered important by RW when assessing children with ID’s pain; (2) whether children's verbal ability impacts pain assessment factors considered; (3) RW assessment and management approach. PARTICIPANTS: Fifty-six RW (18-67 years, Mage=33.37, 46 female). PROCEDURE/MEASURES: In an online survey, participants read and responded to six vignettes manipulating child verbal ability (verbal, nonverbal) and pain source. RESULTS: The factors most frequently considered when assessing pain were child behavior (range: 20-57.4%), and history (e.g., pain, general; 3.7-38.9%). Factors did not vary by child’s verbal ability. RW indicated varied assessment and management-related actions (range: 1-11) for each scenario. DISCUSSION: Findings suggest: a) factors informing pain assessment did not depend on whether or not the child was verbal and b) a degree of flexibility in RW response to pain across situations. While these

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findings are encouraging, ensuring RW have adequate pain assessment and management knowledge specific to children with ID is critical.


Some children with intellectual disabilities (ID): experience pain more frequently than children without ID, express their pain differently, and are incapable of providing self-reports. No research has examined disability and pain-related beliefs of respite workers (RW) and their relations to pain assessment and management decisions for children with ID. OBJECTIVES: (1) compare disability and pain-related beliefs between RW and a sample with little experience in ID; (2) determine whether individuals' beliefs and personal characteristics are related to pain assessment and management decisions. PARTICIPANTS: Fifty-six RW (aged: 18-67 years, Mage=33.37, 46 female) and 141 emerging adults (aged: 18-31 years, Mage=19.67, 137 female). PROCEDURE/MEASURES: In an online survey, participants responded to six vignettes depicting pain in children with ID, and completed measures of pain and disability-related beliefs. RESULTS/DISCUSSION: Compared to those without experience, RW held more positive disability-related beliefs, t(192)=4.23, p<0.001. Participants’ pain-related beliefs (e.g., sensitivity to pain) differed depending on severity of the child’s ID and participant group. Participants’ pain-related beliefs predicted care decisions. Results provide initial insight into RW pain-related beliefs about children with ID, and a basic understanding of the relations among pain beliefs, personal characteristics and pain-related decisions.


When and why did you develop an interest in research? It was a passion of mine during my PhD studies at the University of Florida in the United States and continued to be a major priority as a junior faculty member at the University of California in San Francisco. I was one of the first researchers into pain in children.


Pain and distress in the paediatric palliative care population can be very difficult to manage. Clinical scenarios range from the acute management of cancer-related pain at the end of life to the ongoing long-term support of children with complex multimodal pain related to progressive neurological conditions. Understanding the child’s underlying condition, possible causes of pain and their preferred mode of communication are important to the delivery of holistic care. Modification of environmental factors, basic care consideration and non-pharmaceutical measures have a large role to play, alongside conventional analgesics. Medication may also need to be delivered by novel routes such as transdermal patches, continuous subcutaneous infusion of multiple drugs or transmucosal breakthrough analgesic doses. Two cases are used to illustrate approaches to these clinical problems.


Pain is a frequent and significant problem for children with impairment of the central nervous system, with the highest frequency and severity occurring in children with the greatest impairment. Despite the significance of the problem, this population remains vulnerable to underrecognition and undertreatment.
of pain. Barriers to treatment may include uncertainty in identifying pain along with limited experience and fear with the use of medications for pain treatment. Behavioral pain-assessment tools are reviewed in this clinical report, along with other strategies for monitoring pain after an intervention. Sources of pain in this population include acute-onset pain attributable to tissue injury or inflammation resulting in nociceptive pain, with pain then expected to resolve after treatment directed at the source. Other sources can result in chronic intermittent pain that, for many, occurs on a weekly to daily basis, commonly attributed to gastroesophageal reflux, spasticity, and hip subluxation. Most challenging are pain sources attributable to the impaired central nervous system, requiring empirical medication trials directed at causes that cannot be identified by diagnostic tests, such as central neuropathic pain. Interventions reviewed include integrative therapies and medications, such as gabapentinoids, tricyclic antidepressants, alpha-agonists, and opioids. This clinical report aims to address, with evidence-based guidance, the inherent challenges with the goal to improve comfort throughout life in this vulnerable group of children.


CONTEXT: Palliative sedation is a means of relieving intractable symptoms at the end of life, however, guidelines about its use lack consistency. In addition, ethical concerns persist around the practice. There are reports of palliative sedation in the pediatric literature, which highlight various institutional perspectives. OBJECTIVES: This survey of 4786 pediatric providers sought to describe their knowledge of and current practices around pediatric palliative sedation. METHODS: Our survey was administered to pediatricians who care for children at the end of life. The survey assessed agreement with a definition of palliative sedation, as well as thoughts about its alignment with aggressive symptom management. Bivariate analyses using chi2 and analysis of variance were calculated to determine the relationship between responses to closed-ended questions. Open-ended responses were thematically coded by the investigators and reviewed for agreement. RESULTS: Nearly half (48.6%) of the respondents indicated that the stated definition of palliative sedation "completely" reflected their own views. Respondents were split when asked if they viewed any difference between palliative sedation and aggressive symptom management: Yes (46%) versus No (54%). Open-ended responses revealed specifics about the nature of variation in interpretation. CONCLUSIONS: Responses point to ambiguity surrounding the concept of palliative sedation. Pediatricians were concerned with a decreased level of consciousness as the goal of palliative sedation. Respondents were split on whether they view palliative sedation as a distinct entity or as one broad continuum of care, equivalent to aggressive symptom management. Institutional-based policies are essential to clarify acceptable practice, enable open communication, and promote further research.


INTRODUCTION: Procedural sedation and analgesia (PSA) are frequently used for fracture reduction in pediatric emergency departments (ED). Combining intranasal (IN) fentanyl with inhalation of nitrous oxide (N2O) allow for short recovery time and obviates painful and time-consuming IV access insertions. METHODS: We performed a bicentric, prospective, observational cohort study. Patients aged 4-18years were included if they received combined PSA with IN fentanyl and N2O for the reduction of mildly/moderately displaced fracture or of dislocation. Facial Pain Scale Revised (FPS-R) and Face, Leg, Activity, Cry, Consolability (FLACC) scores were used to evaluate pain and anxiety before, during and after procedure. University of Michigan Sedation Score (UMSS), adverse events, detailed side effects and satisfaction of patients, parents and medical staff were recorded at discharge. A follow up telephone call was made after 24-72h. RESULTS: 90 patients were included. There was no difference in FPS-R during the procedure (median score 2 versus 2), but the FLACC score was significantly higher as compared to before (median score 4 versus 0, Delta 2, 95% CI 0, 2). Median UMSS was 1 (95% CI 1, 2). We recorded no serious adverse events. Rate of vomiting was 12% (11/84). Satisfaction was high among participants.
responding to this question 85/88 (97%) of parents, 74/83 (89%) of patients and 82/85 (96%) of physicians would want the same sedation again. CONCLUSION: PSA with IN fentanyl and N2O is effective and safe for the reduction of mildly/moderately displaced fracture or dislocation, and has a high satisfaction rate. https://www.ncbi.nlm.nih.gov/pubmed/28190665


Children are at times asked by clinicians or researchers to rate their pain associated with their past, future, or hypothetical experiences. However, little consideration is typically given to the cognitive-developmental requirements of such pain reports. Consequently, these pain assessment tasks may exceed the abilities of some children, potentially resulting in biased or random responses. This could lead to the over- or under-treatment of children’s pain. This review provides an overview of factors, and specifically the cognitive-developmental prerequisites, that may affect a child’s ability to report on nonpresent pain states, such as past, future, or hypothetical pain experiences. Children’s ability to report on past pains may be influenced by developmental (age, cognitive ability), contextual (mood state, language used by significant others), affective and pain-related factors. The ability to mentally construct and report on future painful experiences may be shaped by memory of past experiences, information provision and learning, contextual factors, knowledge about oneself, cognitive coping style, and cognitive development. Hypothetical pain reports are sometimes used in the development and validation of pain assessment scales, as a tool in assessing cognitive-developmental and social-developmental aspects of children’s reports of pain, and for the purposes of training children to use self-report scales. Rating pain associated with hypothetical pain scenarios requires the ability to recognize pain in another person and depends on the child’s experience with pain. Enhanced understanding of cognitive-developmental requirements of young children’s pain reports could lead to improved understanding, assessment, and treatment of pediatric pain. https://www.ncbi.nlm.nih.gov/pubmed/27429175


BACKGROUND: Children with neurodevelopmental disabilities may be at risk of opioid-induced respiratory depression. We aimed to quantify the risks and effectiveness of morphine nurse-controlled analgesia (morphine-NCA) for postoperative pain in children with neurodevelopmental disabilities.

METHODS: We carried out a retrospective cohort study of 12 904 children who received postoperative i.v. morphine-NCA. Subjects were divided into a neurodevelopmental disability group and a control group. Rates of clinical satisfaction, respiratory depression, and serious adverse events were obtained, and statistical analysis, including multilevel logistic regression using Bayesian inference, was performed.

RESULTS: Of 12 904 patients, 2390 (19%) had neurodevelopmental disabilities. There were 88 instances of respiratory depression and 52 serious adverse events; there were no opioid-related deaths. The cumulative incidence of respiratory depression in the neurodevelopmental disability group was 1.09% vs 0.59% in the control group [odds ratio 1.8 (98% chance that the true odds ratio was >1)]. A significant interaction between postoperative morphine dose and neurodevelopmental disabilities was observed, with higher risk of respiratory depression with increasing dose. Satisfaction with morphine-NCA was very high overall, although children with neurodevelopmental disabilities were 1% more likely to have infusions rated as fair or poor (3.3 vs 2.1%, chi2P<0.001). CONCLUSIONS: Children with neurodevelopmental disabilities were 1.8 times more likely to suffer respiratory depression, absolute risk difference 0.5%; opioid-induced respiratory depression in this group may relate to increased sensitivity to dose-relate respiratory effects of morphine. Morphine-NCA as described was an acceptable technique for children with and without neurodevelopmental disabilities. https://www.ncbi.nlm.nih.gov/pubmed/28100528

PURPOSE: Survivors of cancer may experience higher rates of psychological problems requiring pharmacological interventions than age-matched controls from the general population. This study compares prescription rates of antidepressants in survivors of cancer, diagnosed in childhood, adolescence, or early adulthood, to the rate in age- and gender-matched controls from the Norwegian population. METHODS: Antidepressants prescribed to 5341 cancer survivors, diagnosed <=25 years during 1965-2000, were studied in a population-based cohort by linking data from the following nationwide registries: the Population Registry of Norway, the Cancer Registry of Norway, and the Norwegian Prescription Database. For each survivor, three age- and gender-matched controls were randomly selected from the population. A Cox proportional hazard model was applied to estimate hazard ratios (HRs) of antidepressant prescriptions during 2004-2012 to the survivors with controls as referents.

RESULTS: Survivors had an increased risk of being prescribed antidepressants with crude rates of 26.9/1000 person-years compared with 22.5/1000 person-years in controls (HR 1.19; 95% confidence interval [CI] 1.12-1.28). The relative risk was highest for survivors of central nervous system tumors (HR 1.30; 95% CI 1.04-1.63), leukemias (HR 1.29; 95% CI 1.03-1.63), testicular tumors (HR 1.27; 95% CI 1.04-1.55), and "other tumors" (HR 1.42; 95% CI 1.10-1.84). No effect of age at cancer diagnosis was found. CONCLUSION: Certain groups of survivors of cancer in childhood, adolescence, or young adulthood have a slightly increased risk for being prescribed antidepressants than their peers. The results may indicate an increased prevalence of depression among these survivors, but diagnostic reasons for prescriptions need to be confirmed in clinical studies.


Ketamine is an emerging therapy for pediatric refractory status epilepticus. The circumstances of its use, however, are understudied. The authors described pediatric refractory status epilepticus treated with ketamine from 2010 to 2014 at 45 centers using the Pediatric Hospital Inpatient System database. For comparison, they described children treated with pentobarbital. The authors estimated that 48 children received ketamine and pentobarbital for refractory status epilepticus, and 630 pentobarbital without ketamine. Those receiving only pentobarbital were median age 3 [interquartile range 0-10], and spent 30 [18-52] days in-hospital, including 17 [9-28] intensive care unit (ICU) days; 17% died. Median cost was $148 000 [81 000-241 000]. The pentobarbital-ketamine group was older (7 [2-11]) with longer hospital stays (51 [30-93]) and more ICU days (29 [20-56]); 29% died. Median cost was $298 000 [176 000-607 000]. For 71%, ketamine was given >/=1 day after pentobarbital. Ketamine cases per half-year increased from 2 to 9 (P < .05). Ketamine is increasingly used for severe pediatric refractory status epilepticus, typically after pentobarbital. Research on its effectiveness is indicated.


INTRODUCTION: Children with severe spastic cerebral palsy (CP) are highly limited in daily life activities causing a reduced quality of life (QoL). This is partly due to an increased muscle tone causing pain and contractures. Continuous intrathecal infusion of baclofen (ITB) reduces the spasticity of affected patients. The hypothesis of the present study was that ITB leads to a significant improvement of QoL in non-
ambulant children with CP. PATIENTS AND METHODS: 13 patients (10 male, 3 female, mean age 14 years) were included. Mean time between pump implantation and follow-up was 60 months (range, 12-100). QoL was assessed before and after baclofen pump implantation using standardized questionnaires (CP CHILD, KINDL). Spasticity was evaluated using the modified Ashworth Scale (MAS) at the two time points. RESULTS: QoL evaluated with the CPCHILD questionnaire and the KINDL improved from pre-implantation to follow-up. MAS markedly decreased from 3.8 to 1.7. All interviewed participants indicated that their expectations had been met and that they would choose ITB treatment again. CONCLUSION: Intrathecal treatment of baclofen is an excellent method for spasticity management in children with severe cerebral palsy. Quality of life sustainably improves, parents’ satisfaction is high and the level of spasticity decreases. Therefore, baclofen treatment can be highly recommended in non-ambulant children with CP suffering from spasticity.


BACKGROUND: Cannabis extracts have a wide therapeutic potential but in many countries they have not been approved for treatment in children so far. OBJECTIVE: We conducted an open, uncontrolled, retrospective study on the administration of dronabinol to determine the value, efficacy, and safety of cannabis-based medicines in the treatment of refractory spasticity in pediatric palliative care. DESIGN AND PARTICIPANTS: Sixteen children, adolescents and young adults having complex neurological conditions with spasticity (aged 1.3-26.6 years, median 12.7 years) were treated with dronabinol by our specialized pediatric palliative care team between 01.12.2010 and 30.04.2015 in a home-care setting. Therapeutic efficacy and side effects were closely monitored. RESULTS: Drops of the 2.5% oily tetrahydrocannabinol solution (dronabinol) were administered. A promising therapeutic effect was seen, mostly due to abolishment or marked improvement of severe, treatment resistant spasticity (n = 12). In two cases the effect could not be determined, two patients did not benefit. The median duration of treatment was 181 days (range 23-1429 days). Dosages to obtain a therapeutic effect varied from 0.08 to 1.0 mg/kg/d with a median of 0.33 mg/kg/d in patients with a documented therapeutic effect. When administered as an escalating dosage scheme, side effects were rare and only consisted in vomiting and restlessness (one patient each). No serious and enduring side effects occurred even in young children and/or over a longer period of time. CONCLUSIONS: In the majority of pediatric palliative patients the treatment with dronabinol showed promising effects in treatment resistant spasticity.


Importance: Early palliative care integration for cancer patients is now touted as the optimal care model, yet significant barriers often prevent its implementation. A perceived barrier, especially for pediatric oncology patients, is the notion that patients and their families may not need or want palliative care involvement early in the disease trajectory. Objective: To determine the perception of symptom burden early in treatment and assess attitudes toward early integration of palliative care in pediatric oncology patient-parent pairs. Design, Setting, and Participants: Novel but pretested survey tools were administered to 129 patient-parent dyads of hospital-based pediatric oncology ambulatory clinics and inpatient units between September 2011 and January 2015. All patient participants were aged between 10 and 17 years and were diagnosed as having an oncologic condition 1 month to 1 year before enrollment. Both the patient and the parent in the dyad spoke English, and all participating parents provided written informed consent. A convenience sample was used for selection, with participants screened when otherwise presenting at a participating site. A total of 280 eligible participants were approached for study inclusion, 258 of whom were enrolled in the study (92.1% positive response-rate). Main Outcomes and Measures: Degree of perceived suffering from early symptom-related causes, attitudes toward early palliative care integration, and patient-parent concordance. Statistical analysis
included descriptive statistics, calculation of concordance, McNemar test results, and Cochran-Armitage trend test results. Results: Of the 129 patients in the dyads, 68 were boys, and 61 girls; of the 129 parents, 15 were men, and 114 women. Patients reported the following symptoms in the first month of cancer therapy: nausea (n = 109; 84.5%), loss of appetite (n = 97; 75.2%), pain (n = 96; 74.4%), anxiety (n = 77; 59.7%), constipation (n = 69; 53.5%), depression (n = 64; 49.6%), and diarrhea (n = 52; 40.3%). A large proportion of those reporting suffering indicated substantial suffering severity from specific symptoms (ie, a great deal or a lot) including nausea, 52.3% (57 of 109), loss of appetite, 50.5% (49 of 97), constipation 30.4% (21 of 69), pain 30.2% (29 of 96), anxiety 28.6% (22 of 77), depression 28.1% (18 of 64), and diarrhea 23.1% (12 of 52). Few children and parents expressed opposition to early palliative care involvement (2 [1.6%] and 8 [6.2%]) or perceived any detrimental effects on their relationship with their oncologist (6 [4.7%] and 5 [3.9%]), loss of hope (3 [2.3%] and 10 [7.8%]), or therapy interference (3 [2.3%] and 2 [1.6%], respectively). Intradyad concordance was low overall: 26% to 29% for exact concordance and 40% to 69% for agreement within 1 response category. Significant differences in patient-parent attitudes toward aspects of early palliative care included child participants being more likely than their parents (40.3% [n = 52] vs 17.8% [n = 23]) to indicate that palliative care would have been helpful for treating their symptoms (P < .001). Conclusions and Relevance: Pediatric oncology patients experience a high degree of symptom-related suffering early in cancer therapy, and very few patients or parents in this study expressed negative attitudes toward early palliative care. Our findings suggest that pediatric oncology patients and families might benefit from, and are not a barrier to, early palliative care integration in oncology.


BACKGROUND: Compared with nociceptive pain, neuropathic pain is a challenging diagnosis to make and successfully treat in children with cancer. OBJECTIVE: The objective of this case report was to see whether very-low-dose methadone (VLDM) (defined as <50% of accepted starting analgesic dose of methadone for children) would be an effective strategy to treat refractory neuropathic pain due to vincristine in two children with acute lymphoblastic leukemia. METHODS: This case report is based on the clinical experience and parent-reported outcomes of two children with refractory neuropathic pain who received VLDM. RESULTS: Based on parent/caregiver-reported outcome scores over a one-year period, both children’s refractory neuropathic pain syndrome was successfully treated with the addition of VLDM to their pre-existing regimen of gabapentin. Neither child suffered any adverse effects from methadone. CONCLUSIONS: VLDM shows promise as an effective, safe, and inexpensive way to treat refractory neuropathic pain in children with cancer.


BACKGROUND: Children and infants with impaired swallow or compromised enteral absorption require alternative routes for administration of analgesia. Recent clinical guidance and practice for paediatric palliative care teams, who often treat such children, supports buccal morphine sulphate as a fast acting, effective and easily administered agent for pain relief. However, a consideration of the physicochemical properties and potency of morphine would suggest that it is not a suitable candidate for delivery via the transmucosal route, raising questions about its use in children and infants. AIM: To explore the permeability of buccal morphine sulphate in an established ex vivo porcine buccal mucosa as a necessary step in examining efficacy for use in children with life-limiting conditions and life-threatening illnesses. DESIGN: A permeation study conducted with morphine sulphate in an ex vivo porcine buccal tissue model. Flux values and pharmacokinetic data were used to calculate the plasma values of morphine that would result following buccal administration in a 20kg child. RESULTS: Results show that the estimated steady state plasma values of morphine sulphate following buccal administration in this model do not achieve minimum therapeutic concentration. CONCLUSION: These data strongly suggest...
that morphine sulphate is not suitable for buccal administration and that further research is needed to establish its efficacy in relief of pain in children with life-limiting conditions and life-threatening illnesses. [1]


Dystonias can arise from any painful stimuli in neurologically disabled children. Classically, feed induced dystonias from mediastinal pain due to severe gastroesophageal reflux disease are described as Sandifer’s spasm. We report a case series of 12 severely neurologically impaired children with enteral feed induced dystonias. Intestinal dysmotility was demonstrated in several. Improvements are seen with jejunal feeds or gut rest with Total Parenteral Nutrition. Use of parenteral nutrition in children with severe neurodisability requires thorough discussion with patient groups and commissioners to give clinicians guidelines to standardise care. [2]


PURPOSE OF REVIEW: Pain management presents a major challenge in neonatal care. Newborn infants who require medical treatment can undergo frequent invasive procedures during a critical period of neurodevelopment. However, adequate analgesic provision is infrequently and inconsistently provided for acute noxious procedures because of limited and conflicting evidence regarding analgesic efficacy and safety of most commonly used pharmacological agents. Here, we review recent advances in the measurement of infant pain and discuss clinical trials that assess the efficacy of pharmacological analgesia in infants. RECENT FINDINGS: Recently developed measures of noxious-evoked brain activity are sensitive to analgesic modulation, providing an objective quantitative outcome measure that can be used in clinical trials of analgesics. SUMMARY: Noxious stimulation evokes changes in activity across all levels of the infant nervous system, including reflex activity, altered brain activity and behaviour, and long-lasting changes in infant physiological stability. A multimodal approach is needed if we are to identify efficacious and well tolerated analgesic treatments. Well designed clinical trials are urgently required to improve analgesic provision in the infant population. [3]


OBJECTIVES: Children presenting with acute traumatic pain or in need of therapeutic or diagnostic procedures require rapid and effective analgesia and/or sedation. Intranasal administration (INA) promises to be a reliable, minimally invasive delivery route. However, INA is still underused in Germany. We hence developed a protocol for acute pain therapy (APT) and urgent analgesia and/or sedation (UAS). Our aim was to evaluate the effectiveness and safety of our protocol. METHODS: We performed a prospective observational study in a tertiary children’s hospital in Germany. Pediatric patients aged 0 to 17 years requiring APT or UAS were included. Fentanyl, s-ketamine, midazolam, or combinations were delivered according to protocol. Primary outcome variables included quality of analgesia and/or sedation as measured on age-appropriate scales and time to onset of drug action. Secondary outcomes were adverse events and serious adverse events. RESULTS: One hundred pediatric patients aged 0.3 to 16 years were enrolled, 34 for APT and 66 for UAS. The median time onset of drug action was 5 minutes (ranging from 2 to 15 minutes). Fentanyl was most frequently used for APT (n = 19). Pain scores decreased by a median of 4 points (range, 0-10; P < 0.0001). For UAS, s-ketamine/midazolam was most frequently used (n = 25). Sedation score indicated minimal sedation in most cases. Overall success rate after the first attempt was 82%. Adverse events consisted of nasal burning (n = 2) and vomiting (n = 2). No serious adverse events were recorded. CONCLUSIONS: A fentanyl-, s-ketamine-, and midazolam-
based INA protocol was effective and safe for APT and UAS. It should then be considered where intravenous access is impossible or inappropriate.  


BACKGROUND: This is an updated review originally published in 2004 and first updated in 2007. This version includes substantial changes to bring it in line with current methodological requirements. Methadone is a synthetic opioid that presents some challenges in dose titration and is recognised to cause potentially fatal arrhythmias in some patients. It does have a place in therapy for people who cannot tolerate other opioids but should be initiated only by experienced practitioners. This review is one of a suite of reviews on opioids for cancer pain. OBJECTIVES: To determine the effectiveness and tolerability of methadone as an analgesic in adults and children with cancer pain. SEARCH METHODS: For this update we searched CENTRAL, MEDLINE, Embase, CINAHL, and clinicaltrials.gov, to May 2016, without language restriction. We also checked reference lists in relevant articles. SELECTION CRITERIA: We sought randomised controlled trials comparing methadone (any formulation and by any route) with active or placebo comparators in people with cancer pain. DATA COLLECTION AND ANALYSIS: All authors agreed on studies for inclusion. We retrieved full texts whenever there was any uncertainty about eligibility. One review author extracted data, which were checked by another review author. There were insufficient comparable data for meta-analysis. We extracted information on the effect of methadone on pain intensity or pain relief, the number or proportion of participants with 'no worse than mild pain'. We looked for data on withdrawal and adverse events. We looked specifically for information about adverse events relating to appetite, thirst, and somnolence. We assessed the evidence using GRADE and created a 'Summary of findings' table. MAIN RESULTS: We revisited decisions made in the earlier version of this review and excluded five studies that were previously included. We identified one new study for this update. This review includes six studies with 388 participants. We did not identify any studies in children. The included studies differed so much in their methods and comparisons that no synthesis of results was feasible. Only one study (103 participants) specifically reported the number of participants with a given level of pain relief, in this case a reduction of at least 20% - similar in both the methadone and morphine groups. Using an outcome of 'no worse than mild pain', methadone was similar to morphine in effectiveness, and most participants who could tolerate methadone achieved 'no worse than mild pain'. Adverse event withdrawals with methadone were uncommon (12/202) and similar in other groups. Deaths were uncommon except in one study where the majority of participants died, irrespective of treatment group. For specific adverse events, somnolence was more common with methadone than with morphine, while dry mouth was more common with morphine than with methadone. None of the studies reported effects on appetite. We judged the quality of evidence to be low, downgraded due to risk of bias and sparse data. For specific adverse events, we considered the quality of evidence to be very low, downgraded due to risk of bias, sparse data, and indirectness, as surrogates for appetite, thirst and somnolence were used. There were no data on the use of methadone in children. AUTHORS' CONCLUSIONS: Based on low-quality evidence, methadone is a drug that has similar analgesic benefits to morphine and has a role in the management of cancer pain in adults. Other opioids such as morphine and fentanyl are easier to manage but may be more expensive than methadone in many economies. https://www.ncbi.nlm.nih.gov/pubmed/28177515


Pain in neonates is associated with short and long-term adverse outcomes. Data demonstrated that long-term consequences of untreated pain are linked to the plasticity of the neonate’s brain. Sucrose is effective and safe for reducing painful procedures from single events. However, the mechanism of
Sucrose-induced analgesia is not fully understood. The role of the opioid system in this analgesia using the opioid receptor antagonist Naltrexone was investigated, plus the long-term effects on learning and memory formation during adulthood. Pain was induced in rat pups via needle pricks of the paws. Sucrose solution and/or naltrexone were administered before the pricks. All treatments started on day one of birth and continued for two weeks. At the end of 8 weeks, behavioral studies were conducted to test spatial learning and memory using radial arm water maze (RAWM), and pain threshold via foot-withdrawal response to a hot plate. The hippocampus was dissected; levels of brain derived neurotrophic factor (BDNF) and endorphins were assessed using ELISA. Acute repetitive neonatal pain increased pain sensitivity later in life, while naltrexone with sucrose decreased pain sensitivity. Naltrexone and/or sucrose prevented neonatal pain induced impairment of long-term memory, while neonatal pain decreased levels of BDNF in the hippocampus; this decrease was averted by sucrose and naltrexone. Sucrose with naltrexone significantly increased beta-endorphin levels in noxiously stimulated rats. In conclusion, naltrexone and sucrose can reverse increased pain sensitivity and impaired long-term memory induced by acute repetitive neonatal pain probably by normalizing BDNF expression and increasing beta-endorphin levels.


AIMS: To review the efficacy and safety of aprepitant in combination with ondansetron and dexamethasone (triple therapy) in children and adolescents on moderate to highly emetogenic chemotherapy. METHODS: Medline, Embase, Scielo, Lilacs, Cochrane and congress abstracts published until September 2016 were used as data sources. Two reviewers independently selected manuscripts and extracted data. A third reviewer solved discrepancies in study selection and data extraction. The primary outcome was overall complete response (no vomiting from 0 to 120 h). Secondary outcomes were: response in acute phase, delayed phase and reported toxicities. Each study was considered a unit of analysis. Summarized relative risks were recalculated based on reported data. All meta-analyses used a random-effects model and heterogeneity was reported using the I2 method. RESULTS: From 1004 studies, we screened 288 titles and abstracts and included three trials for data extraction. The population comprised 451 patients. Most patients were males, ranging from 6 months to 19 years of age, and weighing from 6 to 134 kg. Bone cancer was the most incident (> =50%) neoplasm, followed by rhabdomyosarcoma and Hodgkin’s lymphoma. Triple therapy was associated with a reduced risk of developing chemotherapy-induced vomiting (CIV) (RR = 0.48; 95% CI 0.34-0.67). There were no differences in incidence of febrile neutropenia between groups (RR = 1.02; 95% CI 0.66-1.58). CONCLUSIONS: Triple therapy decreased CIV risk, without increasing the occurrence of febrile neutropenia. However, this review could not address which subpopulations would most benefit from using this strategy. Future studies should focus on assessing risk factors for nausea and vomiting, as many patients did not achieve a complete antiemetic response.


CONTEXT: Specialized pediatric palliative care (PPC) services have become more common in urban pediatric hospital settings, although little is known about palliative care specialist involvement. OBJECTIVES: The objective of this study was to compare circumstances before death in children who spent their last days of life in an inpatient pediatric hospital setting, with or without PPC provider involvement during their inpatient stay. METHODS: Retrospective chart review of medical records of children for the last inpatient stay that resulted in death at a children’s hospital setting between January 2012 through June 2013. The setting was a free-standing, 385-bed tertiary care children’s hospital. RESULTS: Charts were reviewed for 114 children between 0 and 18 years of age, who were hospitalized for at least 24 hours before their death. Half of the children who died as inpatients were infants (median
Children who received an inpatient PPC consult (25% of the sample) experienced 1) a higher rate of pain assessments, 2) better documentation around specific actions to manage pain, 3) greater odds of receiving integrative medicine services, 4) fewer diagnostic/monitoring procedures (e.g., blood gases, blood draws, placements of intravenous lines) in the last 48 hours of life, and 5) nearly eight times greater odds of having a do-not-resuscitate order in place at the time of death. CONCLUSION: The integration of a PPC team was associated with fewer diagnostic/monitoring procedures and improved pain management documentation in this study of 114 children who died as inpatients.


The intranasal route for medication administration is increasingly popular in the emergency department and out-of-hospital setting because such administration is simple and fast, and can be used for patients without intravenous access and in situations in which obtaining an intravenous line is difficult or time intensive (e.g., for patients who are seizing or combative). Several small studies (mostly pediatric) have shown midazolam to be effective for procedural sedation, anxiolysis, and seizures. Intranasal fentanyl demonstrates both safety and efficacy for the management of acute pain. The intranasal route appears to be an effective alternative for naloxone in opioid overdose. The literature is less clear on roles for intranasal ketamine and dexmedetomidine.


Continuous positive airway pressure (CPAP) requires nasopharyngeal suctioning for airway patency, which is painful. Other procedures have used breast milk and 25% dextrose as analgesics. We aimed to compare their analgesic efficacy during nasopharyngeal suctioning in preterm neonates on CPAP. In this blinded randomized controlled trial, babies received 25% dextrose or breast milk orally. Pain before, during and after was assessed using the Premature Infant Pain Profile (PIPP) score. Analysis was done for 40 babies. The mean PIPP score in the 25% dextrose group during the procedure was 11.25 +/- 2.73 and 13.2 +/- 2.55 (p = 0.02) with the intervention and without. In the breast milk group the PIPP score during the procedure was 11.35 +/- 3.05 and 13.45 +/- 3.27 (p = 0.04); this difference persisted even after the procedure. There was no significant difference between the interventions. Both interventions significantly reduce pain. The analgesic effect of breast milk was sustained.


OBJECTIVE: To evaluate the safety, efficacy and effective dosage of clonidine in the outpatient (OP) management of secondary dystonia. METHODS: A retrospective analysis of children and young people (CAYP) prescribed clonidine in an OP clinic between January 2011 and November 2013 for dystonia management. Of 224 children receiving clonidine, 149/224 did not have a movement disorder and 12/224 had no data leaving 63 movement disorder cases, 15/63 managed as in-patients, 15/48 suffered from tics leaving 33/63 for OP evaluation. Clonidine effectiveness was assessed by ‘yes/no’ criteria in improving 5 areas: seating, sleep, pain, tone and involuntary movements. RESULTS: 2/33 motor cases had insufficient data; 7/33 had concurrent therapy leaving 24/33 for analysis. Improvement in at least one area was reported by 20/24 (83%) CAYP: Improved seating tolerance 14/24, and sleep 15/24; reduced pain 15/24; improved tone 16/24 and involuntary movements 17/24. Starting doses ranged from 1 mcg/kg OD to 2 mcg/kg TDS with optimum doses reached on average at 9.5 months follow-up. Maximum dose reached was 75 mcg/kg/day given in 8 divided doses. Average maximum daily dose
was 20 mcg/kg/day. The commonest frequency of administration was 8 hourly. Side effects were reported in 11/24 CAYP and discontinued in 1/24 for lack of clinical effectiveness, 1/24 for side effects and 4/24 due to both lack of effectiveness and side effects. CONCLUSION: Clonidine was effective in secondary dystonia management in 83% of cases. A starting dose of 1 mcg/kg TDS was well tolerated and safely escalated. Prospective objective evaluation is now required to confirm the efficacy of clonidine.


BACKGROUND: Despite technological advances in the neonatal intensive care unit, not all infants survive. Limited research has focused on infants’ symptoms and suffering at end of life (EOL) from multiple perspectives. PURPOSE: To compare retrospective parent report and electronic medical record (EMR) documentation of symptoms and to examine associations with parent perceptions of infants suffering at EOL. METHODS/SEARCH STRATEGY: Bereaved parents of 40 infants (40 mothers and 27 fathers) retrospectively reported on their perceptions of infant symptoms and suffering during the last week of life. EMRs were also reviewed. FINDINGS/RESULTS: Parents were asked about their observations of 23 symptoms. Within the 27 parental dyads, mothers reported 6.15 symptoms (standard deviation = 3.75), which was not significantly different from fathers' report of 5.67 symptoms (standard deviation = 5.11). Respiratory distress, agitation, and pain were most common according to mothers and EMR, whereas respiratory distress, agitation, and lethargy were most common according to fathers. Few differences were found between mothers, fathers, and EMRs. However, missing data (range: 0%-20%) indicated that some parents had challenges assessing symptoms. Parents reported that the worst symptom was respiratory distress. In addition, parents reported moderate infant suffering, which was correlated with the total number of symptoms. IMPLICATIONS FOR PRACTICE: Parents demonstrate awareness of their infant’s symptoms at EOL, and these observations should be valued as they closely parallel EMR documentation. However, some parents did have difficulty reporting symptoms, highlighting the importance of education. IMPLICATIONS FOR RESEARCH: Future larger sample research should prospectively examine parent perceptions of infant symptom burden, suffering, and associations with other infant and parent outcomes (eg, decision making and grief).


Gastroesophageal reflux disease (GERD) is a very common condition and affects approximately 7-20% of the pediatric population. Symptoms from pathological GERD include regurgitation, irritability when feeding, respiratory problems, and substernal pain. Treatment typically starts with dietary modifications and postural changes. Antireflux medications may then be added. Indications for operative management in the pediatric population include failure of medical therapy with poor weight gain or failure to thrive, continued respiratory symptoms, and complications such as esophagitis. Laparoscopic Nissen fundoplication has become the standard of care for surgical treatment of children with GERD. The key technical aspects of laparoscopic Nissen fundoplication include creation of an adequate intra-abdominal esophagus, minimal dissection of the hiatus with exposure of the right crus to identify the gastroesophageal junction, crural repair, and creation of floppy, 360 degrees wrap that is oriented at the 11 oclock position.


Children and adolescents with highly disabling chronic pain of high intensity and frequency are admitted to specialized pain rehabilitation programs. Some barriers to obtaining this specialized care include a lack of availability of treatment centers, a perceived social stigma and individual barriers such as socioeconomic status. Specialized rehabilitation programs for severe disabling chronic pain worldwide have similarities regarding admission criteria, structure and therapeutic orientation. They differ, however, regarding their exclusion criteria and program descriptions. The short- and long-term effectiveness of some rehabilitation programs is well documented. All countries should promote the establishment of future pediatric pain centers to improve the health care of children and adolescents suffering from severe chronic pain. Standardized reporting guidelines should be developed to describe treatments and outcomes to enable comparability across treatment centers.


BACKGROUND: The Pediatric Palliative and Comfort Care Team (PACT) at Cincinnati Children's Hospital Medical Center (CCHMC) provides opioids to a large population of patients in the ambulatory setting. Before this project, PACT had no reliable system to risk stratify patients for opioid misuse. METHODS: The global aim was safe opioid prescribing by the palliative care team. The specific, measurable, achievable, realistic, and timely aim was as follows: "In patients who present for follow up with PACT, we will use the "opioid bundle" to increase risk stratification for opioid misuse from 0% to 90% over 5 months." The opioid bundle includes a urine drug screen, Ohio Automated Rx Reporting System report, pill count, and screening history for drug abuse and mental health disorders. The setting was multiple CCHMC ambulatory clinics. Participants included all PACT members. RESULTS: Since implementing the new system, we have increased risk stratification for opioid misuse among outpatients from 0% to >90%. Results have been sustained for 12 months. Key processes have become reliable: obtaining informed consent and controlled substance agreements for all new patients and obtaining the opioid bundle to enable risk stratification in a consistent and timely fashion. A total of 34% of patients have been stratified as high risk, and an additional 27% have been stratified as moderate risk. CONCLUSIONS: A system to ensure safe opioid prescribing practices to all patients is critical for providers. Identifying key processes and executing them reliably has enabled the palliative care team at CCHMC to risk stratify >90% of patients receiving opioids in the ambulatory setting for opioid misuse.


BACKGROUND: Pain may be reported in one-half to three-fourths of children with cancer and other terminal conditions and anxiety in about one-third of them. Pharmacologic methods do not always give satisfactory symptom relief. Complementary therapies such as Reiki may help children manage symptoms. OBJECTIVE: This pre-post mixed-methods single group pilot study examined feasibility, acceptability, and the outcomes of pain, anxiety, and relaxation using Reiki therapy with children receiving palliative care. METHODS: A convenience sample of children ages 7 to 16 and their parents were recruited from a palliative care service. Two 24-minute Reiki sessions were completed at the children’s home. Paired t tests or Wilcoxon signed-rank tests were calculated to compare change from pre to post for outcome variables. Significance was set at P < .10. Cohen d effect sizes were calculated. RESULTS: The final sample included 8 verbal and 8 nonverbal children, 16 mothers, and 1 nurse. All mean scores for outcome variables decreased from pre- to posttreatment for both sessions. Significant decreases for pain for treatment 1 in nonverbal children (P = .063) and for respiratory rate for treatment 2 in verbal children (P = .009). Cohen d effect sizes were medium to large for most outcome measures. DISCUSSION: Decreased mean scores for outcome measures indicate that Reiki therapy did decrease
pain, anxiety, heart, and respiratory rates, but small sample size deterred statistical significance. This preliminary work suggests that complementary methods of treatment such as Reiki may be beneficial to support traditional methods to manage pain and anxiety in children receiving palliative care. 


Despite advances in psychological interventions for pediatric chronic pain, there has been little research examining mindfulness meditation for these conditions. This study presents data from a pilot clinical trial of a six-week manualized mindfulness meditation intervention offered to 20 adolescents aged 13-17 years. Measures of pain intensity, functional disability, depression and parent worry about their child’s pain were obtained at baseline and post-treatment. Results indicated no significant changes in pain or depression, however functional disability and frequency of pain functioning complaints improved with small effect sizes. Parents’ worry about child’s pain significantly decreased with a large effect size. Participants rated intervention components positively and most teens suggested that the number of sessions be increased. Three case examples illustrate mindfulness meditation effects and precautions. Mindfulness meditation shows promise as a feasible and acceptable intervention for youth with chronic pain. Future research should optimize intervention components and determine treatment efficacy.


BACKGROUND: Pain management in hospitalized children is often inadequate. The prevalence and main sources of pain in Danish university hospitals is unknown. METHODS: This prospective mixed-method cross-sectional survey took place at four university hospitals in Denmark. We enrolled 570 pediatric patients who we asked to report their pain experience and its management during the previous 24 hours. For patients identified as having moderate to severe pain, patient characteristics and analgesia regimes were reviewed. RESULTS: Two hundred and thirteen children (37%) responded that they had experienced pain in the previous 24 hours. One hundred and thirty four (24%) indicated moderate to severe pain and 43% would have preferred an intervention to alleviate the pain. In children hospitalized for more than 24 hours, the prevalence of moderate/severe pain was significantly higher compared to children admitted the same day. The single most common painful procedure named by the children was needle procedures, such as blood draw and intravenous cannulation. CONCLUSION: This study reveals high pain prevalence in children across all age groups admitted to four Danish university hospitals. The majority of children in moderate to severe pain did not have a documented pain assessment, and evidence-based pharmacological and/or integrative (‘non-pharmacological’) measures were not systematically administered to prevent or treat pain. Thus, practice changes are needed.

Psychosocial and Family Issues


Background Studies have documented the experiences of families with seriously ill children, but few have focused on the spiritual needs of families confronted with a child's imminent death.


The present study aimed to examine whether bereaved parents "meaning-made"-defined as results of attempts to reduce discrepancies between the meaning assigned to the death of the child and self and world-views-was influenced by their own and their partner’s coping orientations. Coping orientations were conceptualized within the Dual Process Model, which entails loss coping orientation (LO; focus on the loss itself), restoration coping orientations (RO; focus on stressors that come about as an indirect consequence of the bereavement), and a flexible oscillation between both coping orientations. The sample consisted of 227 couples identified through obituary notices in local and national newspapers, who provided data at 6, 13, and 20 months after the death of their child. At all three points of measurement, both partners independently completed the Dual Coping Inventory (DCI) and a scale developed by the authors about meaning-made from the loss. Data were analyzed using a multi-level Actor-Partner Interdependence Model. Results show that the combination of parents' own LO and RO (operationalized through the interaction effect between LO and RO) have a positive effect in parents' meaning-made. Partners' LO have a negative effect in parents' meaning-made. These results highlight the importance of, in the context of parental bereavement, being flexible by using both coping orientations, and of acknowledging the interdependence between partners, namely, the interpersonal process by which partner’s coping affect one's meaning-made.


PURPOSE: To determine the effect of the drawing and writing technique on the anxiety level of children undergoing cancer treatment in hospital. METHOD: Research was conducted in the haematology-oncology clinic of a university hospital, using a quasi-experimental design (pre-and-post intervention evaluations of a single group). The sample comprised 30 hospitalised children aged 9-16 years. Data were collected with Socio-demographic form, clinical data form, and the State Anxiety Inventory. The institution gave written approval for the study and parents provided written consent. Drawing, writing and mutual story-telling techniques were used as part of a five-day programme. Children were asked to draw a picture of a hospitalised child and write a story about this drawing. After drawing and writing, mutual storytelling were used to create a constructive story with positive feelings. The drawing, writing techniques was implemented on the first and third days of the programme and mutual storytelling was implemented on the second and fourth days. Data were reported as percentages and frequencies and the intervention effect analysed with the Wilcoxon test. RESULTS: The average age of children was 12.56 years +/- 2.67 and 76.7% were girls. The mean age diagnosis and mean treatment duration were 11.26 years +/- 3.17 and 16.56 months +/- 20.75 respectively. Most of the children (50%) had leukaemia and were receiving chemotherapy (66.7%). In most cases (76.7%) the mother was the primary caregiver. Scores on the State Anxiety Inventory were lower-indicating lower anxiety-after the intervention (36.86 +/- 4.12 than...
before it (40.46 +/- 4.51) (p < 0.05). CONCLUSION: The therapeutic intervention reduced children's state anxiety. https://www.ncbi.nlm.nih.gov/pubmed/28478846


BACKGROUND: Children's books have the potential to facilitate communication about death for children living with a serious illness and for children coping with the death of a loved one. OBJECTIVES: This study examines the content of children's literature relevant to the topic of dying and death and identifies books providers can share with children and their families. DESIGN: A search of children's literature was conducted using four electronic databases and one additional search engine using the word "Death" or "Dying." Storybooks about dying, death, and bereavement published in English, French, or Spanish between 1995 and 2015 were included. MEASUREMENTS: Each book underwent content analysis by at least two independent reviewers. Strict PRISMA standard was followed. Full protocol is available as PROSPERO #CRD42016042129. RESULTS: Two hundred ten books met inclusion criteria. The dying subject was primarily a grandparent (n = 78) or pet (n = 44). Books on the experience of a child dying were scarce (n = 5). The word death or dying was used in 75% of the books (n = 158), while others utilized euphemisms. The majority of books featured animals (n = 40) or Caucasian subjects (n = 122) and included spiritual elements such as heaven (n = 122). Less than one-quarter of the books included tools for readers to address the topic of death. CONCLUSIONS: Storybooks can be a helpful tool to introduce communication about dying and death with children. Gaps exist in current children's literature to effectively enable children to reflect on their own dying process. A general summary of available books is provided to assist those caring for children and families facing end-of-life issues. https://www.ncbi.nlm.nih.gov/pubmed/28346862


This study provides detailed data on the current characteristics, perceptions and outcomes of 45 young people with cystic fibrosis (CF) as they transition into adulthood. Although many had severe disease, they generally coped well, found attendance at a transition clinic helpful and welcomed the increased independence of an adult healthcare environment. Levels of psychological distress were low with only 15.6% having anxiety and 6.7% depression. The main psychological coping strategy used was optimistic acceptance. Overall, most remained stable after transfer but 33% had some decline in lung function and 9% in nutritional status, requiring intensification of treatment. They had high levels of satisfaction with their relationships and life situations and 76% were in employment or education. These results are encouraging and as life expectancy improves, young adults with CF are coping well with transition into adulthood. https://www.ncbi.nlm.nih.gov/pubmed/28365620


BACKGROUND: Unexpected death of a loved one (UD) is the most commonly reported traumatic experience in cross-national surveys. However, much remains to be learned about posttraumatic stress disorder (PTSD) after this experience. The WHO World Mental Health (WMH) survey initiative provides a unique opportunity to address these issues. METHODS: Data from 19 WMH surveys (n = 78,023; 70.1% weighted response rate) were collated. Potential predictors of PTSD (respondent sociodemographics, characteristics of the death, history of prior trauma exposure, history of prior mental disorders) after a
representative sample of UDAs were examined using logistic regression. Simulation was used to estimate overall model strength in targeting individuals at highest PTSD risk. RESULTS: PTSD prevalence after UD averaged 5.2% across surveys and did not differ significantly between high-income and low-middle income countries. Significant multivariate predictors included the deceased being a spouse or child, the respondent being female and believing they could have done something to prevent the death, prior trauma exposure, and history of prior mental disorders. The final model was strongly predictive of PTSD, with the 5% of respondents having highest estimated risk including 30.6% of all cases of PTSD. Positive predictive value (i.e., the proportion of high-risk individuals who actually developed PTSD) among the 5% of respondents with highest predicted risk was 25.3%. CONCLUSIONS: The high prevalence and meaningful risk of PTSD make UD a major public health issue. This study provides novel insights into predictors of PTSD after this experience and suggests that screening assessments might be useful in identifying high-risk individuals for preventive interventions.


PURPOSE: The aim of this study was to illuminate parents' lived experiences of losing a child to cancer. METHOD: Interviews and a narrative about parents' experiences of losing a child to cancer were gathered from six parents of children whom had participated in a longitudinal study across the child's illness trajectory. The analysis of the data was inspired by van Manen's hermeneutic phenomenological approach. RESULTS: One essential theme emerged: Like being covered in a wet and dark blanket, as well as six related themes: Feeling conflicting emotions, Preparing for the moment of death, Continuing parenting after death, Recollecting and sharing memories, Working through the sorrow and New perspectives in life. CONCLUSION: There is a need for good palliative care. If not, there is a risk that the parent will perseverate and blame themselves for not being a good parent during the suffering child's last time in life. Meetings with the parents six months and two years after the child's death might facilitate healing through the grief process.


It is estimated that rare diseases affect the lives of over three million people in the United Kingdom. Of these, a significant proportion are children and young people with genetic life-limiting or life-shortening conditions. This study used a qualitative approach with in-depth semi-structured interviews to explore the experiences of 10 adult siblings of a baby diagnosed with Trisomy 13 (Patau syndrome) or Trisomy 18 (Edward syndrome). Findings illustrate that parental grief from the time of their child’s diagnosis onward is also experienced by siblings. Although young adults may have conflicting feelings as a bereaved sibling, there is evidence that the experience impacts on their world views and their attitudes about prospective and expectant parenthood. The study highlights the importance of providing siblings with short-term and long-term support from the time of their brother’s or their sister’s diagnosis onward and provides new understanding about benefit of professional and peer support in helping young adults develop resilience and coping strategies.


The present research focused on bereaved parents' perceived grief similarity, and aimed to investigate the concurrent and longitudinal effects of the perceptions that the partner has less, equal, or more grief intensity than oneself on relationship satisfaction. Participants of our longitudinal study were 229 heterosexual bereaved Dutch couples who completed questionnaires 6, 13, and 20 months after the loss of their child. Average age of participants was 40.7 (SD = 9.5). Across 3 study waves, participants’ perceived grief similarity and relationship satisfaction were assessed. To control for their effects, own grief level, child’s gender, expectedness of loss, parent’s age, parent’s gender, and time were also included in the analyses. Consistent with the hypotheses, cross-sectional results revealed that bereaved parents who perceived dissimilar levels of grief (less or more grief) had lower relationship satisfaction than bereaved parents who perceived similar levels of grief. This effect remained significant controlling for the effects of possible confounding variables and actual similarity in grief between partners. We also found that perceived grief similarity at the first study wave was related to the highest level of relationship satisfaction at the second study wave. Moreover, results showed that perceived grief similarity was associated with a higher level in partner’s relationship satisfaction. Results are discussed considering the comparison and similarity in grief across bereaved partners after child loss. (PsycINFO Database Record https://www.ncbi.nlm.nih.gov/pubmed/27732005)


Continuing a bond after a loved one’s death is considered typical and healthy. However, such a bond can continue symbolically only if it existed in the first place. What of indirect griever, those who never knew the deceased? The authors describe bonds between individuals who did not have a living relationship to begin with, a concept referred to as imagined bonds. Forty-nine adults, who had a sibling die that they never knew, were interviewed. This article describes the bonds constructed between participants and the sibling they never knew. The authors compare and contrast the concepts of continuing bonds versus imagined bonds. https://www.ncbi.nlm.nih.gov/pubmed/28140777


Palliative care for infants, children, and adolescents encompasses numerous transitions and thresholds of uncertainty that challenge conventional clinical medicine. Palliative care clinicians have opportunities to be more comfortable amid such challenges, or perhaps even overcome them, if they are attuned to the unique times and places in which patients, their families, and caregivers find themselves throughout illness and recovery or transitioning toward the end of life. Patient-clinician encounters often dwell in these liminal places. The concept of liminality gives validation to the patient or family’s being "stuck in places betwixt and between" a past life rich with relationship and purpose and an acute, chronic, or critical illness. Or having resolved the acute crisis of hospitalization that place between the past bounds of illness and the uncertain path forward, perhaps even toward death. Liminality provides a framework for addressing the unbound spaces that patients and families occupy: What is past is behind-the present place is tenuous and temporary, and what is ahead uncertain. This place is where palliative care clinicians can offer clinicians and families guidance. https://www.ncbi.nlm.nih.gov/pubmed/26861443


Informal caregivers (IC) are key to enabling home deaths, where preferred, at the end-of-life. Significant morbidity from advanced cancer can make caregiving burdensome. However, knowledge about the
nature of the caregiving burden for caregivers in Singapore is limited. Hence, the key objective in this study was to examine the impact of the caregiving burden on quality of life (QOL), mental health and work capacity among local ICs. Eligible English-speaking ICs of hospitalized advanced cancer patients were recruited through non-random sampling. The Zarit Burden Interview (ZBI), Caregiver Quality of Life Index-Cancer (CQOLC), Center for Epidemiologic Studies Depression Scale-Revised (CESD-R), and Work Productivity and Activity Impairment Questionnaire (WPAI) were interviewer-administered to eligible ICs. Altogether, 16 ICs were surveyed. The mean age of ICs was 43.8 years. Most were children of patients (43.8%), and eight ICs had high burden (ZBI > 17). Those with ZBI > 17 had lower QOL, higher depression scores as well as greater work and activity impairment. In conclusion, high caregiver burden has adverse effects on QOL, mental health and work productivity. Non-physical elements of caregiving (particularly financial and decision-making) and increased number of care roles undertaken by a single IC contribute to high burden. Future interventions for caregiving burden in Singapore should also address the financial and decision-making aspects of caregiving. Outsourcing selected aspects of the caregiving role to community services may reduce the number of caregiving aspects undertaken by a single IC and caregiver burden.


BACKGROUND: Experiential studies in paediatric palliative care are needed to enable an ongoing international agenda which supports the development of responsive family supports. AIM: To provide an in-depth exploration of the prevalent lived experiences of parents who are currently providing care for a child with a life-limiting condition in Australia. DESIGN: Cross-sectional, prospective, qualitative study guided by an advisory group and reported according to the consolidated criteria for reporting qualitative studies. Transcripts were subjected to a thematic analysis, underpinned by an interpretative phenomenological framework. SETTING/PARTICIPANTS: Purposively sampled parents (n = 14) recruited from a statewide paediatric hospice who self-identified as a 'primary caregiver' for one or more children and/or adolescents (18 years) with a life-limiting condition. RESULTS: Four key themes represented the prevalent experiences of parents: (1) trapped inside the house, (2) the protector, (3) living with the shadow and (4) travelling a different pathway. They describe parents’ physical and social isolation, exclusion from the workforce, pervasive grief and associated impacts to their health and well-being. Limited professional and diminished social supports resulted in full ownership of care responsibility. Yet, parents embraced their role as 'protector', reporting acquired meaning and purpose. CONCLUSION: This study builds upon the growing body of evidence available in paediatric palliative care internationally. The key themes highlight the substantial demand for both physical and emotional support beyond what is currently offered and call for the implementation of carefully planned support services and other societal initiatives which seek to alleviate the broad health impacts to caregivers.


BACKGROUND: Policy guidance and bioethical literature urge the involvement of adolescents in decisions about their healthcare. It is uncertain how roles and expectations of adolescents, parents and healthcare professionals influence decision-making and to what extent this is considered in guidance. AIMS: To identify recent empirical research on decision-making regarding care and treatment in adolescent cancer: (1) to synthesize evidence to define the role of adolescents, parents and healthcare professionals in the decision-making process and (2) to identify gaps in research. DESIGN: A narrative systematic review of qualitative, quantitative and mixed-methods research. We adopted a textual approach to synthesis, using a theoretical framework of interactionism to interpret findings. DATA SOURCES: The databases MEDLINE, PsycINFO, SCOPUS, EMBASE and CINHAL were searched from 2001 through May 2015 for publications on decision-making for adolescents (13-19 years) with cancer.
RESULTS: Twenty-eight articles were identified. Adolescents and parents initially find it difficult to participate in decision-making due to a lack of options in the face of protocol-driven care. Parent and adolescent preferences for information and response to loss of control vary between individuals and over time. No studies indicate parental or adolescent preference for a high degree of independence in decision-making. CONCLUSION: Striving to make parents and adolescents fully informed or urge them towards more independence than they prefer may add to distress and confusion. This may interfere with their ability to participate in their preferred way in decisions about care and treatment. Future research should include analysis of on-ground interactions among parents, adolescents and clinicians across the trajectory.


Illness narratives have become very popular. The stories of children, however, are rarely ever studied. This paper aims to provide insight into how children, parents and physicians make sense of progressive childhood cancer. It also explores how this meaning-giving process interacts with cultural dominant stories on cancer and dying. The presented data come from 16 open-ended face-to-face interviews with palliative paediatric patients, their parents and physicians. The interviews were carried out in eight paediatric oncology centres in Switzerland. Data analysis followed Arthur Frank’s dialogical narrative analysis. Quest narratives were relatively rare compared to both chaos and restitution stories. All participants welcomed chaos stories as a liminal haven between quest and restitution. The possibility that the child could die was either ignored or briefly contemplated, but then immediately pushed away. Except for one patient, children never directly addressed the topic of death. The way in which death was presented raises important questions about how the social discourse on dying is framed in terms of choice, autonomy and individuality. This discourse not only determines the way in which children and adults relate to the minor’s death, it also constitutes an obstacle to children’s participation in decision-making.


BACKGROUND: Communication with parents about end-of-life care and decisions is a difficult and sensitive process. The objective of the present study was to ascertain clinicians’ views on the acceptability and usefulness of a handbook and web-based resource (Caring Decisions) that was designed as an aid for parents facing end-of-life decisions for their child. METHODS: Qualitative interviews were conducted with a range of health professionals who provide care to children facing life-limiting conditions. RESULTS: Data analysis confirmed the acceptability and usefulness of the resource. Two major themes were revealed: 1. Family empowerment, with sub-themes Giving words and clarity, Conversation starter, 'I'm not alone in this', and A resource to take away, highlighted how the resource filled a gap by supporting and enabling families in a multitude of ways; 2. Not just for families, with sub-themes A guide for staff, When to give the resource?, How to give the resource and Who should give the resource?, explored the significant finding that participants viewed the resource as a valuable tool for themselves, but its presence also brought into relief potential gaps in communication processes around end-of-life care. CONCLUSION: The interview data indicated the positive reception and clear value and need for this type of resource. However, it is likely that successful resource uptake will be contingent on discussion and planning around dissemination and use within the health care team.


Bereaved parents have higher morbidity and mortality rates when compared to nonbereaved parents. Although parental grief is well studied, the complexities of challenges bereaved parents face are not understood. This study describes parental bereavement challenges during the first 6 months following the death of their child. The complex parental bereavement challenges are characterized by the absence of the child, their emotional response, and the changed relationships with family and friends. The adaptive leadership framework is a useful framework to identify and classify challenges. Future research can use this framework to provide a structure that test interventions to address the challenges.


Parents confronting the death of a child or working through the complex health needs of a child often feel isolated in their communities. They seek a personal connection with others who are going through similar emotions. Faith's Lodge is a unique respite for those families to find a place to reflect, find peace, and more.


Sibling relationships reflect a unique childhood bond, thus the impact on a sibling when a child is seriously ill or dying is profound. We conducted a prospective, longitudinal, qualitative study over 2 years using interpretive descriptive methodology to understand siblings’ perspectives when a brother or sister was dying at home or in hospital. The insights from the 10 siblings revealed complex experiences, both personal and with the ill child, their families, and peers. These experiences were paradoxically sources of strain and of support, revealing the importance of validation and normalization in assisting siblings to successfully navigate the experience.

AIM: To understand parents’ experiences and needs during a child’s end-of-life care at home and to identify systemic factors that influence its provision. BACKGROUND: A child’s end-of-life phase is an extremely difficult time for the whole family. Parents have specific needs, especially when they care for a dying child at home. DESIGN: Concurrent embedded mixed methods design. METHODS: This sub-study of the nationwide survey, 'Paediatric End-of-Life Care Needs in Switzerland' (2012-2015) included 47 children who received EOL care at home from 2011-2012. We extracted quantitative data from patients’ medical charts and obtained information via parental questionnaire and then compared parents whose child died at home or in hospital by computing generalized estimation equations. We thematically analysed interviews with parents who provided EOL care at home. RESULTS: Parents created an intimate lifeworld and a sense of normality for the child at home. They constantly balanced the family’s lifeworld with the requirements and challenges posed by the outside world. This work exhausted parents. Parental ‘readiness’ and social support drove EOL care for children at home. Parents needed practical help with housekeeping and had negative experiences when dealing with insurance. In only 34.8% of cases was a child’s EOL home care supported by paediatric palliative care team. CONCLUSION: Paediatric end-of-life care at home is only feasible if parents make extraordinary efforts. If family-centred end-of-life home care is provided by a hospital-based paediatric palliative home care team, which includes paid housekeeping help and psychological support, parents' needs could be better met. https://www.ncbi.nlm.nih.gov/pubmed/28329430


Young adult survivors of childhood cancer (N = 47) completed essays exploring situational coping within a mixed methods study. Data were qualitatively analyzed using consensual qualitative research-modified methodology. Five themes emerged: (1) initial reactions to cancer, (2) adjustment/coping with cancer diagnosis and treatment, (3) provisions of social support, (4) perceived effects of cancer experience, and (5) reflections on the cancer experience. Perceptions of childhood cancer experiences appear generally positive, with the majority of negative reactions emerging immediately following diagnosis. Cognitive behavioral and supportive interventions may be most beneficial in the initial postdiagnosis period and should emphasize lasting benefits, accomplishments, and profound effects. https://www.ncbi.nlm.nih.gov/pubmed/28332951


This study explores triadic intergenerational perceptions of family members' beliefs and behaviors that often impact an individual’s willingness to engage in advance care planning. Using data from 189 triads of young adults, their parents, and their grandparents, we examined generational relationships among individuals’ openness about death, death anxiety, knowledge of surrogate decision-making, and advance care planning self-efficacy. Results of this study found significant relationships between grandparents and parents, as well as between parents and children for all variables except self-efficacy. Additionally, results of this study found indirect relationships between grandparents and their grandchildren for three variables. These findings underscore the need to treat advance care planning as a family communication issue. Implications for how advance care planning should be approached in conversations with healthcare providers and within the family are discussed. https://www.ncbi.nlm.nih.gov/pubmed/28441102

BACKGROUND: This study explored psychological adjustment and sibling relationships of siblings of children with life-limiting conditions (LLCs), expanding on previous research by defining LLCs using a systematic classification of these conditions. METHODS: Thirty-nine siblings participated, aged 3-16 years. Parents completed measures of siblings' emotional and behavioural difficulties, quality of life, sibling relationships and impact on families and siblings. Sibling and family adjustment and relationships were compared with population norms, where available, and to a matched comparison group of siblings of children with autistic spectrum disorder (ASD), as a comparable 'high risk' group. RESULTS: LLC siblings presented significantly higher levels of emotional and behavioural difficulties, and lower quality of life than population norms. Their difficulties were at levels comparable to siblings of children with ASD. A wider impact on the family was confirmed. Family socio-economic position, time since diagnosis, employment and accessing hospice care were factors associated with better psychological adjustment. CONCLUSIONS: Using a systematic classification of LLCs, the study supported earlier findings of increased levels of psychological difficulties in siblings of children with a LLC. The evidence is (i) highlighting the need to provide support to these siblings and their families, and (ii) that intervention approaches could be drawn from the ASD field.


BACKGROUND: In many countries there are now detailed Child Death Review (CDR) processes following unexpected child deaths. CDR can lead to a fuller understanding of the causes for each child's death but this potentially intrusive process may increase the distress of bereaved families. In England, a joint agency approach (JAA) is used where police, healthcare and social services investigate sudden child deaths together and a key part of this is the joint home visit (JHV) where specialist police and paediatricians visit the home with the parents to view the scene of death. This study aimed to learn of bereaved parents' experiences of JAA investigation following Sudden Unexpected Death in Infancy (SUDI). METHODS: This was a qualitative study of joint agency investigation of SUDI by specialist police, healthcare and social services including case note analysis, parental questionnaires, and in-depth interviews with parents and professionals. Families were recruited at the conclusion of the JAA. Data were analysed using a Framework Approach. RESULTS: 21/113 eligible families and 26 professionals participated giving theoretical saturation of data. There was an inherent conflict for professionals trying to both investigate deaths thoroughly as well as support families. Bereaved parents appreciated the JAA especially for the information it provided about the cause of death but were frustrated with long delays waiting to obtain this. Many parents wanted more emotional support to be routinely provided. Most parents found the JHV helpful but a small minority of mothers found this intensely distressing. In comparison to JHVs, when police visited death scenes without paediatricians, information was missed and parents found these visits more upsetting. There were issues with uniformed non-specialist police traumatising parents by starting criminal investigations and preventing parents from accessing their home or collecting vital possessions. CONCLUSIONS: Overall most parents feel supported by professionals during the JAA; however there is scope for improvement. Paediatricians should ensure that parents are kept updated with the progress of the investigations. Some parents require more emotional support and professionals should assist them in accessing this.


OBJECTIVE: To explore prospective mothers’ perspectives regarding antenatal consultations by neonatology teams for threatened preterm delivery. STUDY DESIGN: In a prospective multicenter study, women at risk of preterm delivery between 26 and 32 weeks of gestational age were surveyed during the 72 hours following their antenatal consultation. The questionnaire used was developed and validated during a single-center study. RESULTS: Over 18 months, 229 mothers completed the survey (73%
response rate), at a median gestational age of 30 weeks. Spouses/partners were present for 49% of consultations. Most women (90%) reported a positive experience. They found it important to discuss the outcomes of prematurity (66%), but 39% of them reported receiving too much information. Women wanted their spouse/partner to be present (71%) and wished to discuss parental concerns: their roles as mother of a premature baby (82%), their integration in their baby’s care (83%), and a better understanding of the neonatal intensive care unit (NICU) environment, including antenatal NICU visits (69%). The majority (56%) wanted a follow-up consultation: this was less likely if a NICU visit had been offered (P < .001), if their role as decision-maker had been discussed (P < .05), or if the consultation had lasted longer (P = .001). CONCLUSION: Policy statements recommend a standardized approach to providing parents with child-centered information. Although clinicians follow these guidelines, mothers want personalized information focusing on their individual concerns and questions, such as what they can do for their baby, how NICUs work, and the integration of their family.


Ignorance is generally pictured as an unwanted state of mind, and the act of willful ignorance may raise eyebrows. Yet people do not always want to know, demonstrating a lack of curiosity at odds with theories postulating a general need for certainty, ambiguity aversion, or the Bayesian principle of total evidence. We propose a regret theory of deliberate ignorance that covers both negative feelings that may arise from foreknowledge of negative events, such as death and divorce, and positive feelings of surprise and suspense that may arise from foreknowledge of positive events, such as knowing the sex of an unborn child. We conduct the first representative nationwide studies to estimate the prevalence and predictability of deliberate ignorance for a sample of 10 events. Its prevalence is high: Between 85% and 90% of people would not want to know about upcoming negative events, and 40% to 70% prefer to remain ignorant of positive events. Only 1% of participants consistently wanted to know. We also deduce and test several predictions from the regret theory: Individuals who prefer to remain ignorant are more risk averse and more frequently buy life and legal insurance. The theory also implies the time-to-event hypothesis, which states that for the regret-prone, deliberate ignorance is more likely the nearer the event approaches. We cross-validate these findings using 2 representative national quota samples in 2 European countries. In sum, we show that deliberate ignorance exists, is related to risk aversion, and can be explained as avoiding anticipatory regret. (PsycINFO Database Record


identified. Such programs should be included in a holistic approach to improve the psychological outcomes of parents whose children are receiving treatment for cancer. 


The aim of this study was to explore the use of religious songs in response to stressful life events among young African American adults. Fifty-five young African American adults aged 18-49 participated in a qualitative study involving criterion sampling and open-ended interviews. Data analysis included content analysis and descriptive statistics. Stressful life events were related to work or school; caregiving and death of a family member; and relationships. Religious songs represented five categories: Instructive, Communication with God, Thanksgiving and Praise, Memory of Forefathers, and Life after Death. The tradition of using religious songs in response to stressful life events continues among these young adults. Incorporating religious songs into health-promoting interventions might enhance their cultural relevance to this population.


When a family member dies, a bereavement period is taking place for all family members. The death of a parent during childhood is a highly stressful event. This study evaluates families' experiences of family support groups when a parent has died. Families were participate in groups for children, teenagers, young adults, and parents in seven sessions. The same topic which was discussed in all groups. The support groups were evaluated qualitatively and quantitatively. The participants were satisfied with the groups and experienced that the shared experience facilitated bereavement to proceed. The results indicate that families' experiences is being more open about feelings in their own family. A support group can be one possibility to help the whole family in the bereavement.


CONTEXT: Parents of a seriously ill child may have different concerns and hopes for their child, and these concerns and hopes may change over time. OBJECTIVES: In a mixed-method prospective cohort of parental dyads of children with serious illness, to describe the major problems and hopes perceived for their child, examine the degree of concordance between parents, and assess whether prevalence and concordance change over time. METHODS: Eighty-four parents (42 dyads) of seriously ill children reported the major problems and hopes for their children at baseline. Thirty-two parents (16 dyads) answered the same questions at 24 months. Problems and hopes were classified into nine domains. Observed concordance was calculated between parents on each domain. Data for parents of 11 children who died are reported separately. RESULTS: The most common major problem and hope domains at baseline were physical body, quality of life, future health and well-being, and medical care. Parental dyads demonstrated a moderately high percentage of concordance (69%) regarding reported problem domains and a slightly lower percentage of concordance on hopes (61%), with higher concordance for more common domains. Domain prevalence and concordance changed considerably at 24 months. Parents of children who later died showed markedly different patterns of domain prevalence and more extreme patterns of concordance. CONCLUSION: Parents of children with serious illness may have different perspectives regarding major problems and hopes, and these perspectives change over time. Parents of sicker children are more likely to be in either complete agreement or disagreement regarding the problems and hopes they identify.

AIMS: A systematic review was conducted to appraise and classify evidence related to the life transitions of adolescents and young adults with life-limiting conditions. METHODS: The databases searched were MEDLINE, CINAHL, PsycINFO, CancerLit, and AMED. Methodological quality was assessed using an established tool and the final articles included in the study were rated as moderate to high quality. Articles were then assessed based on the insight that they provided into life transitions for adolescents and young adults. RESULTS: Eighteen studies were included in the final review, with two major life transitions identified as pertinent: 'illness transition' and 'developmental transition'. These concurrent transitions were found to be relevant to adolescents and young adults with life-limiting conditions, generating complex needs. Sub-themes within the transitions were also identified. Furthermore, the illness transition was found to also impact significant others, namely family members, having physical, mental and emotional health implications and requiring them to make adaptations. CONCLUSIONS: Future research is needed to focus on adolescent and young adult perspectives to bring further insight into these key transitions, since such perspectives are currently underrepresented. Attention to the impact of the illness on the whole family would be useful to expand findings from this review. https://www.ncbi.nlm.nih.gov/pubmed/27992275


AIM: This study was conducted to evaluate the effect of narrative writing on the satisfaction of the mothers with care in the neonatal intensive care unit (NICU) during their neonates' hospitalization. MATERIALS AND METHODS: This quasi-experimental study with pretest and posttest were administered to a sample size of 70 mothers with preterm neonates. The Neonatal Index of Parental Satisfaction questionnaire was used. Descriptive and analytical statistics were used for data analysis. RESULTS: The satisfaction level of the mothers was 113.1 +/- 17.5 on the 3rd day and 102.3 +/- 25.6 on the 10th day of the study in the control group. Paired t-test (p values < 0.011) in the control group showed a significant difference in the satisfaction level of the mothers. In the intervention group, the satisfaction level of the mothers was 107.5 +/- 21.5 on the 3rd day and 137 +/- 15.2 on the 10th day of the study. Paired t-test (p values < 0.001) showed a significant difference in the satisfaction level of the mothers between the 3rd and 10th day of the study. The results of independent t-test showed a significant difference in satisfaction between the intervention and control groups on the 10th day of the study (p < 0.001). CONCLUSION: We suggest that narrative writing may be considered as an efficient supportive intervention to increase the mothers' satisfaction in the NICUs. https://www.ncbi.nlm.nih.gov/pubmed/27112919


The current paper presents a summary of a 12-year body of research on final conversations, which will be useful for healthcare providers who work with patients and family nearing the end-of-life, as well as for patients and their family members. Final conversations encompass any and all conversations that occur between individuals with a terminal diagnosis and their family members (all participants are aware that their loved one is in the midst of the death journey). Final conversations take the family member’s perspective and highlights what are their memorable messages with the terminally ill loved one. In this paper the authors highlight the message themes present at the end-of-life for both adults and children, the functions each message theme serves for family members, and lastly, the communicative challenges of final conversations. Additionally, the authors discuss the current nature and future of final

Purpose: There has been increased awareness recently of the unique medical and psychosocial needs of adolescents and young adults (AYAs) with cancer. However, the existing AYA literature is mainly focused on curative disease or survivorship rather than on advanced disease. Using qualitative methodology, we sought to understand the experience of younger adults with advanced cancer.

Methods: Participants were interviewed using open-ended, discovery-oriented interviews. Data was analyzed using thematic analysis. In total, ten English-speaking advanced cancer patients who were being treated at a comprehensive cancer center in Canada, were interviewed. Participants were between the ages of 18 and 35, and seven of them were female.

Results: The diagnosis of cancer was universally experienced as isolating and unexpected, with serious illness regarded as a problem of older individuals. The core challenge of living in the face of dying was felt to be constantly present yet typically unarticulated. Meaning-making tended to be constructed around future-oriented goals rather than upon the life that had been lived. Individuals felt forcefully removed from the stream of life, with a perceived interruption in the developmental tasks of establishing adult identity, becoming autonomous, and forming new relationships. All cited a need for young adult-specific services, yet none could describe specific services that would be beneficial. Many expressed reluctance to engage in individual psychotherapeutic treatment.

Conclusions: Advanced cancer in younger adults was perceived by them as isolating and as interfering with age-appropriate developmental tasks. Creative and flexible psychosocial support programs are needed to engage this population with limited expected survival.


Survivors of pediatric brain tumors experience several medical and psychosocial late effects including deficits in social competence. This mixed methods study investigated the experience of 19 adolescent and young adult survivors of pediatric brain tumors and 17 parents who participated in a social support program. Qualitative results demonstrated a significant social isolation that was compounded by medical late effects. Survivors perceived social support and acceptance from interactions with peers who have similar medical backgrounds as a key aspect of the group experience. Parents reported increased social confidence among survivors, although they did not report that social gains generalized beyond the group setting. Interventions to promote the transfer of specific social skills are needed.


Background: Pediatric advance care planning is advocated by healthcare providers because it may increase the chance that patient and/or parent wishes are respected and thus improve end-of-life care. However, since end-of-life decisions for children are particularly difficult and charged with emotions, physicians are often afraid of addressing pediatric advance care planning. Aim: We aimed to investigate parents' views and needs regarding pediatric advance care planning. Design: We performed a qualitative interview study with parents of children who had died from a severe illness. The interviews were analyzed by descriptive and evaluation coding according to Saldana. Setting/participants: We conducted semi-structured interviews with 11 parents of 9 children. Maximum variation was sought
regarding the child’s illness, age at death, care setting, and parent gender. RESULTS: Parents find it difficult to engage in pediatric advance care planning but consider it important. They argue for a sensitive, individualized, and gradual approach. Hope and quality of life issues are primary. Parents have many non-medical concerns that they want to discuss. Written advance directives are considered less important, but medical emergency plans are viewed as necessary in particular cases. Continuity of care and information should be improved through regular pediatric advance care planning meetings with the various care providers. Parents emphasize the importance of a continuous contact person to facilitate pediatric advance care planning. CONCLUSION: Despite a need for pediatric advance care planning, it is perceived as challenging. Needs-adjusted content and process and continuity of communication should be a main focus in pediatric advance care planning. Future research should focus on strategies that facilitate parent engagement in pediatric advance care planning to increase the benefit for the families. https://www.ncbi.nlm.nih.gov/pubmed/27881828


Researchers today consider childhood bereavement one of the most traumatic experiences that can befall a child. Nevertheless, most models of bereavement currently limit themselves to dealing with adult grief and primarily explores the internal processes associated with recovery. Based on a study which conducted focus groups with 39 Danish adolescents (aged 9-17), this article presents The Model of Loss Navigation in Adolescence. Centered on the three factors-Being Different, Being in Control, and Being in Grief-the model highlight the social conventions children have to navigate and how these influences both their day-to-day lives and their road to recovery. https://www.ncbi.nlm.nih.gov/pubmed/28060580


BACKGROUND: With more care taking place in the home, family carers play an important role in supporting patients. Some family carers undertake technical health procedures generally managed by health professionals in hospital settings (e.g. managing a tracheostomy or enteral feeding). AIM: To explore how family carers learn to manage technical health procedures in order to help health professionals better understand and support this process. DESIGN AND METHODS: A grounded theory study using data from interviews with 26 New Zealand family carers who managed technical health procedures including nasogastric or gastrostomy feeding, stoma care, urinary catheterisation, tracheostomy management, intravenous therapy, diabetes management and complex wound dressings. Most (20 participants) were caring for their child and the remaining six for their spouse, parent or grandparent. Following grounded theory methods, each interview was coded soon after completion. Additional data were compared with existing material, and as analysis proceeded, initial codes were grouped into higher order concepts until a core concept was developed. Interviewing continued until no new ideas emerged and concepts were well defined. FINDINGS: The core concept of ‘wayfinding’ indicates that the learning process for family carers is active, individualised and multi-influenced, developing over time as a response to lived experience. Health professional support was concentrated on the initial phase of carers’ training, reducing and becoming more reactive as carers took responsibility for day-to-day management. CONCLUSION: Wayfinding involves self-navigation by carers, in contrast to patient navigator models which provide continuing professional assistance to patients receiving cancer or chronic care services. Wayfinding by carers raises questions about how carers should be best supported in their initial and ongoing learning as the management of these procedures changes over time. https://www.ncbi.nlm.nih.gov/pubmed/28124508

OBJECTIVE: To explore recipients' perspectives on the range and origins of their emotional experiences during their 'bad news' consultations. METHODS: Participants were four bereaved families of children who had changed from active treatment to palliative care in paediatric oncology. Data was collected using emotional touchpoint storytelling. The names (descriptors) given to the emotional experiences were linguistically classified. Explanations of their perceived origins were examined using applied thematic analysis. RESULTS: 26 descriptors were given, relating to bodily sensations, affective states, evaluations and cognitive conditions. Three themes were identified in the origins of these experiences - 'becoming aware', 'the changes' and 'being in this situation'. Parents described strong emotional displays during the consultation including physical collapse. These related to the internal process of 'becoming aware'. Three descriptors were given as originating from the clinicians and their delivery of the news - 'supported', 'included', 'trusting'. CONCLUSIONS: Recipients perceive their emotional experiences as mainly originating from the news itself, and perceived consequences of it, rather than its delivery. Strong emotional reactions during the interaction are not necessarily an indicator of ineffectual delivery. PRACTICE IMPLICATIONS: Findings offer a thematic framing that may support and deepen practitioners understanding of recipients' emotional reactions during bad news consultations.


To review the qualitative literature on experiences of and preferences for end-of-life care of people with cancer aged 16-40 years (young adults) and their informal carers. A systematic review using narrative synthesis of qualitative studies using the 2006 UK Economic and Social Research Council research methods program guidance. Seven electronic bibliographic databases, two clinical trials databases, and three relevant theses databases were searched from January 2004 to October 2015. Eighteen articles were included from twelve countries. The selected studies included at least 5% of their patient sample within the age range 16-40 years. The studies were heterogeneous in their aims, focus, and sample, but described different aspects of end-of-life care for people with cancer. Positive experiences included facilitating adaptive coping and receiving palliative home care, while negative experiences were loss of "self" and nonfacilitative services and environment. Preferences included a family-centered approach to care, honest conversations about end of life, and facilitating normality. There is little evidence focused on the end-of-life needs of young adults. Analysis of reports including some young adults does not explore experience or preferences by age; therefore, it is difficult to identify age-specific issues clearly. From this review, we suggest that supportive interventions and education are needed to facilitate open and honest communication at an appropriate level with young people. Future research should focus on age-specific evidence about the end-of-life experiences and preferences for young adults with cancer and their informal carers.


This study addressed parental spirituality in the context of pediatric cancer with a poor prognosis. Drawing upon previous research implementing a longitudinal grounded theory design examining parental hope, 35 parents were interviewed regarding their experiences with an emergent description of the role of spirituality in parents’ daily lives. Spirituality included religious beliefs and practices, notions of a higher force or cosmos, relationship with a divine being, as well as elements emerging from meaning-making and relationships. Parental expectations of spirituality remained relatively constant across data collection
time points (3-9 months postdiagnosis), although limited variation occurred relative to shifting circumstance (e.g., deterioration of the child's condition). Spirituality appeared to offer: greater acceptance of parents’ inability to protect their child from harm related to her/his life-threatening illness, guidance and emotion decompression, and support from one’s faith community. Recommendations for integrating spiritual assessment in clinical care practice are offered.


PURPOSE: Chronic sorrow is a multidimensional concept experienced by mothers of children suffering with chronic conditions, e.g. cancer. Little is known about the concept of chronic sorrow and related issues/experiences among mothers of children with cancer living in Iran. This study aimed to explore the concept of chronic sorrow, based on the lived experiences of chronic sorrow experienced in a group of Iranian mothers of children with cancer. METHODS: In this hermeneutic phenomenological study, 8 mothers of children with cancer participated in semi structured, in-depth interviews about their experiences of chronic sorrow. Interviews continued until data saturation was reached. All interviews were recorded, transcribed, analyzed, and interpreted using the seven steps of the Dickelman et al.’s phenomenological approach. RESULTS: The three main themes that emerged from mothers' experiences of chronic sorrow related to their child's cancer were "climbing up shaky rocks," "religious fear and hope," and "continuous role changing." Each of these themes consisted of several subthemes. Besides the possibility of growth and coping with the chronic condition of a child which has been seen in other studies on chronic sorrow experiences, religious issues were more profound than what has reported in Western studies. Also the ambiguous prognosis and uncertain process of the cancer in children had made the experience of chronic sorrow more unique. CONCLUSION: The results of this study show that the experiences of mothers of children with cancer in Iran are not specific to them, but are better comprehended in their traditional socio-cultural context.


OBJECTIVE: Life-threatening illnesses in children have a significant impact on the lives of their brothers and sisters. Consequently, special attention must be paid to the specific needs of these siblings to help them cope with their situations. To address this issue, we developed an inventory of the needs of the adolescent siblings of severely ill children, the Inventaire des Besoins de la Fratrie d’Enfants Malades Severement (IBesFEMS) [Needs Inventory for Siblings of Critically Ill Children]. The present article describes a preliminary validation study of this new instrument. METHOD: In a prospective cohort study, the 48-item instrument was administered via a website or paper to 58 siblings. RESULTS: Our study revealed that the measure has an estimated internal consistency of 0.96 and a temporal stability intraclass correlation coefficient (ICC) of 0.86 (p < 0.01). Its convergence validity is also satisfactory. SIGNIFICANCE OF RESULTS: Our findings suggest that the IBesFEMS is highly relevant for pediatric palliative care clinicians and researchers. Future studies should investigate its factorial structure and predictive validities.


OBJECTIVE: The presence of a child afflicted with a life-threatening illness is a difficult situation for the child’s siblings, especially when their own needs are left unmet. The present article describes the first three phases of research involved in the conceptualization, development, and content validation of an initial version of the Inventaire des Besoins de la Fratrie d’Enfants Malades Severement (IBesFEMS)
[Needs Inventory for Siblings of Critically ill Children]. METHOD: The first phase of the development of this instrument was conducted using qualitative methodology (focus groups: 6 siblings, 8 parents). The second phase consisted of validating the content of a pool of items developed according to the needs identified in the first phase. Some 21 participants (3 psychometricians, 3 researchers, 9 clinicians, and 6 siblings) evaluated each item for relevance and clarity. Finally, during the third phase, the acceptability and administration procedures of the preliminary version of the instrument were assessed qualitatively by five siblings. RESULTS: The first phase led to production of a typology made up of 43 needs in 10 different environments. The second phase allowed for selection of the items that were clearest and most relevant, based on expert opinion. This procedure gave rise to a first version of the IBesFEMS, which consisted of 48 items. SIGNIFICANCE OF RESULTS: The IBesFEMS appears to be a promising tool for specifically assessing the needs of the adolescent siblings of seriously ill children.


This study seeks to explore the potential implications of Facebook use in the process of maternal grief. The participants were 11 women who had lost their children due to accidents or prolonged illness. Semistructured interviews were conducted and subjected to thematic analysis. The participants stated that they used Facebook to receive support, to identify with other mothers, to remember the child who died, to access the child’s information, to honor him/her, and to express their feelings. The use of Facebook can play a very important role in the initial phase of grieving due to the functions of this social network.


The illness and death of someone close is a big challenge that affects individuals and the whole system. To understand how children, adolescents and young adults experience the death of a significant other, and more specifically a family member, it is necessary to consider aspects of developmental psychology, the life-cycle phase of the family and the systemic view on the burden and reactions from individuals and the whole system. Palliative care and in particular family-oriented counselling and therapy stabilizes the system. Support of the adult caregiver, facilitating understanding of each other even if there are divergent needs as well as the support of sincere communication are important strategies. Children and adolescents as well as their families are supported to find their coherent way to deal with the imminent death of a close one and to integrate the experience into the biography with maximum mental wellbeing.


PURPOSE: The prevalence of intimacy and substance use among adolescents and young adults during cancer therapy has not been well described. METHODS: The "Resilience in Adolescents and Young Adults with Cancer" study was a prospective, multicenter, mixed-methods cohort study. English-speaking patients 14-25 years old with newly diagnosed cancer were invited to complete a comprehensive survey at the time of enrollment (T1) and 3-6 months later (T2). Intimate relationships and health behaviors were assessed with questions adapted from the Guidelines for Adolescent Preventative Services assessment. Descriptive statistics characterized the prevalence of sexual and substance-related behaviors at each time point. RESULTS: Of 42 eligible and enrolled participants, 35 (83%) and 25 (69%) completed T1 and T2 surveys, respectively. Their mean age was 17.6 years (standard deviation 2.3), 57% were male, and the most common diagnoses were sarcoma and acute leukemia. Over a third of participants reported dating at each time point; 26% were sexually active at T1, and 32% at T2. Of those
endorsing sexual activity, fewer than half reported consistent birth control or condom use and 4 reported their first sexual intercourse during our observation. In addition, 46% (T1) and 44% (T2) reported alcohol use and 23% (T1) and 26% (T2) reported illicit drug use. Despite these activities, fewer than 10% endorsed a worry or need to discuss these behaviors with oncology providers. CONCLUSIONS: Intimacy and substance use among adolescents and young adults are common during cancer therapy. Clinical and research implications include the identification of optimal communication and patient-centered supports.


Parents who experience the loss of a child have unique and valuable insights into the grief journey and can help health care providers identify key components intrinsic to the development, implementation, and maintenance of a comprehensive bereavement program. The bereavement program at St. Jude Children's Research Hospital was developed by pediatric palliative care experts in collaboration with bereaved parents to standardize and improve the institutional support provided to families around and after the death of a child. This article describes the components of a parent-derived bereavement program and presents early results on the effects of specific program components. The program, under the leadership of the bereavement coordinator, includes clinical and supportive interventions offered throughout the grief journey, parent-created bereavement support materials, and opportunities for parents and families to participate in research, quality improvement initiatives and educational interventions. Parents report that services and interventions provided through the bereavement program are beneficial to families after the death of their child. In addition, both health care providers and bereaved parents report that participation in educational interventions positively impacts their experiences as clinicians and parents, respectively. The innovative nature of this parent-driven, comprehensive bereavement program may serve as a paradigm for the development of bereavement programs in the fields of pediatrics, palliative oncology and hospice and palliative medicine.


PURPOSE: For adolescents and young adults (AYAs), the impact of a cancer diagnosis and subsequent treatment is likely to be distinct from other age groups given the unique and complex psychosocial challenges of this developmental phase. In this review of the literature, we report the health-related quality of life (HRQoL) issues experienced by AYAs diagnosed with cancer and undergoing treatment. METHODS: MEDLINE, EMBASE, CINAHL, PsychINFO and the Cochrane Library Databases were searched for publications reporting HRQoL of AYAs. Issues generated from interviews with AYAs or from responses to patient reported outcome measures (PROMs) were extracted. RESULTS: 166 papers were reviewed in full and comprised 72 papers covering 69 primary studies, 49 measurement development or evaluation papers and 45 reviews. Of the 69 studies reviewed, 11 (16%) used interviews to elicit AYAs' descriptions of HRQoL issues. The majority of the PROMs used in the studies represent adaptations of paediatric or adult measures. HRQoL issues were organised into the following categories: physical, cognitive, restricted activities, relationships with others, fertility, emotions, body image and spirituality/outlook on life. CONCLUSION: The HRQoL issues presented within this review are likely to be informative to health care professionals and AYAs. The extensive list of issues suggests that the impact of a cancer diagnosis and treatment during adolescence and young adulthood is widespread and reflects the complexities of this developmental phase.

Objective: The present study examined the role of maternal posttraumatic growth in changes in behavioral problems among the siblings of children with complex chronic health conditions. Methods: Data were collected from a sample of 70 siblings from 58 families with at least one child diagnosed with a life-threatening genetic, metabolic, or neurological condition. Every 6 months for up to 4 years, sibling behavior problems were assessed through both parent-reports and youth self-reports. At each visit, mothers also completed self-reports of posttraumatic growth. Results: Time-lagged multilevel regression analyses revealed that higher levels of maternal posttraumatic growth predicted subsequent declines in parent-reported internalizing, externalizing, and total behavior problems among healthy siblings. These findings were partially replicated using youth self-reports of their own behavior problems. Conclusion: The findings suggest that the benefits of posttraumatic growth may extend beyond the self to other family members, particularly to children in the family.


OBJECTIVE: The importance of spirituality in the dying process is well documented. However, what spirituality means in these situations is hard to discern because few people (patients, families, researchers, or caregivers) will view spirituality in the same way. The present research supports the use of a spiritual framework consisting of five common attributes (meaning, beliefs, connections, self-transcendence, and value) as a mechanism for viewing spirituality for people nearing the end of life. Using qualitative interviews from two related studies, our study aims to describe the prevalence of spirituality and its nature according to these five spiritual attributes. METHODS: Data from two previous studies were analyzed. The first employed the methods of grounded theory to understand the strategies adolescents used to manage the impending death of a parent. Some 61 participants from 26 families were interviewed, including ill parents/patients, well parents/caregivers, and adolescents. The second study consisted of 15 interviews with the surviving parent and adolescents from 6 of these families after the death of the parent. RESULTS: The original research from which these data were drawn did not seek to describe spirituality. However, spiritual themes were prevalent in the stories of many participants and included each of the five spiritual attributes. SIGNIFICANCE OF RESULTS: Our findings demonstrate the prevalence of spirituality in the everyday lives of these families and supports the use of the spiritual framework according to the five common attributes to describe spirituality.


Our objective was to develop a rich description of how parents experience their grief in the first year after the death of their child, and how various bereavement follow-up and support services helped them during this time, with the aim of informing follow-up and support services offered to bereaved parents. Our findings situated parents’ individual experiences of coping within the social and institutional contexts in which they grieved. In the first year after the death of their child, parents regulated their intense feelings of grief through loss-oriented, restoration-oriented, and/or meaning reconstruction strategies. Often, parents' relationships with others and many of the bereavement follow-up and support services helped them in this regard. This article also explores how the results may aid service providers in accompanying parents in a way that optimizes outcomes for these parents.
OBJECTIVE: Advanced care plans (ACPs) are designed to convey the wishes of patients with regards to their care in the event of incapacity. There are a number of prerequisites for creation of an effective ACP. First, the patient must be aware of their condition, their prognosis, the likely trajectory of the illness, and the potential treatment options available to them. Second, patient input into ACP must be free of any coercive factors. Third, the patient must be able to remain involved in adapting their ACP as their condition evolves. Continued use of familial determination and collusion within the local healthcare system, however, has raised concerns that the basic requirements for effective ACP cannot be met.

METHOD: To assess the credibility of these concerns, we employed a video vignette approach depicting a family of three adult children discussing whether or not to reveal a cancer diagnosis to their mother. Semistructured interviews with 72 oncology patients and 60 of their caregivers were conducted afterwards to explore the views of the participants on the different positions taken by the children.

RESULTS: Collusion, family-centric decision making, adulteration of information provided to patients, and circumnavigation of patient involvement appear to be context-dependent. Patients and families alike believe that patients should be told of their conditions. However, the incidence of collusion and familial determination increases with determinations of a poor prognosis, a poor anticipated response to chemotherapy, and a poor premorbid health status. Financial considerations with respect to care determinations remain secondary considerations.

SIGNIFICANCE OF RESULTS: Our data suggest that ACPs can be effectively constructed in family-centric societies so long as healthcare professionals continue to update and educate families on the patient’s situation. Collusion and familial intervention in the decision-making process are part of efforts to protect the patient from distress and are neither solely dependent on cultural nor an "all-or-nothing" phenomenon. The response of families are context-dependent and patient-specific, weighing the patient’s right to know and prepare and the potential distress it is likely to cause. In most cases, the news is broken gently over time to allow the patient to digest the information and for the family to assess how well they cope with the news. Furthermore, the actions of families are dependent upon their understanding of the situation, highlighting the need for continued engagement with healthcare professionals.


OBJECTIVE: Posttraumatic stress disorder (PTSD) and posttraumatic stress symptoms (PTSSs) are common for parents of children with life-threatening illnesses or injuries. The impact of these psychological sequelae on parents’ personal use of health services is unknown. The present study aimed to investigate whether PTSS severity prospectively predicts increased health service utilization (HSU), and to examine the relative importance of other predisposing and enabling factors in predicting HSU.

METHOD: The sample comprised 106 parents of children with various life threatening illnesses, who completed a resource use questionnaire at 19 months following their child’s diagnosis or admission. HSU was assessed as reported general practitioner and psychologist visits. RESULTS: Parent PTSS severity at 7 months following their child’s diagnosis or hospital admission predicted being in higher service utilization categories in the following 12 months; as PTSS score increased, the odds of being in higher categories increased. Hierarchical ordinal logistic regression procedures indicated predisposing and enabling factors failed to further explain HSU. CONCLUSIONS: These findings highlight the importance of PTSSs to HSU and are consistent with studies of samples experiencing other forms of
trauma, such as war or natural disaster. Our results also suggest that an individuals' need, in terms of the severity of their PTSSs, appears most important in predicting their health service engagement. Although this is positive, the effectiveness of this service use, in terms of cost and outcomes, remains unclear. Further, despite the levels of PTSSs observed in the present sample, a minority of individuals sought psychosocial care. (PsycINFO Database Record https://www.ncbi.nlm.nih.gov/pubmed/28530432


In paediatric palliative care (PPC), parents are confronted with increasing caregiving demands. More children are cared for at home, and the need for PPC of children is lengthened due to technical and medical improvements. Therefore, a clear understanding of the content of parental caregiving in PPC becomes increasingly important. The objective is to gain insight into parental caregiving based on the lived experience of parents with a child with a life-limiting disease. An interpretative qualitative study using thematic analysis was performed. Single or repeated interviews were undertaken with 42 parents of 24 children with a malignant or non-malignant disease, receiving PPC. Based on their ambition to be a 'good parent', parents caring for a child with a life-limiting disease strived for three aims: controlled symptoms and controlled disease, a life worth living for their ill child and family balance. These aims resulted in four tasks that parents performed: providing basic and complex care, organising good quality care and treatment, making sound decisions while managing risks and organising a good family life.

CONCLUSION: Parents need early explanation from professionals about balancing between their aims and the related tasks to get a grip on their situation and to prevent becoming overburdened. What is Known: * In paediatric palliative care, parents are confronted with increasing caregiving demands. * Parenting is often approached from the perspective of stress. What is New: * Parents strive for three aims: controlled symptoms and controlled disease, a life worth living for their child and family balance. * Parents perform four tasks: providing basic and complex care, organising good quality care, making decisions while managing risks and organising a good family life. * Professionals need insight into the parents' aims and tasks from the parental perspective to strengthen parents' resilience.  


BACKGROUND: Parents of children with a life-limiting disease have to rely on themselves at home while adequate paediatric palliative care is lacking. In several countries, paediatric palliative care teams are introduced to ensure continuity and quality of care and to support the child and the family. Yet, little is known about how parents experience such multidisciplinary teams. AIM: To obtain insight into the support provided by a new paediatric palliative care team from the parents' perspective. DESIGN: An interpretative qualitative interview study using thematic analysis was performed. SETTING/PARTICIPANTS: A total of 47 single or repeated interviews were undertaken with 42 parents of 24 children supported by a multidisciplinary paediatric palliative care team located at a university children's hospital. The children suffered from malignant or non-malignant diseases. RESULTS: In advance, parents had limited expectations of the paediatric palliative care team. Some had difficulty accepting the need for palliative care for their child. Once parents experienced what the team achieved for their child and family, they valued the team's involvement. Valuable elements were as follows: (1) process-related aspects such as continuity, coordination of care, and providing one reliable point of contact; (2) practical support; and (3) the team members' sensitive and reliable attitude. As a point of improvement, parents suggested more concrete clarification upfront of the content of the team's support. CONCLUSION: Parents feel supported by the paediatric palliative care team. The three
elements valued by parents probably form the structure that underlies quality of paediatric palliative care. New teams should cover these three valuable elements.


**BACKGROUND:** Research on the psychological experiences of parents of infants within pediatric oncology is sparse. This study examined rates and indicative risk factors for psychological distress in parents where there is either an infant patient or infant sibling of a patient. 

**METHODS:** Participants were mothers ($n = 41$) and fathers ($n = 25$) of infants under 2 years who either had a cancer diagnosis ($n = 37$; infant patients) or was an infant sibling of an older child with cancer ($n = 29$; infant siblings) recruited from a single oncology center. There were 21 couple dyads. Parents completed the Depression Anxiety Stress Scales short form and the Posttraumatic Stress Disorder Checklist. 

**RESULTS:** Mothers (47.5%) and fathers (37.5%) reported elevated, cancer-related posttraumatic stress symptoms. Rates of depression (12.2% of mothers and 12.0% of fathers) and anxiety symptoms (17.1% of mothers and 8.0% of fathers) were lower. Compared with parents of infant patients, parents of infant siblings reported significantly higher rates of depressive symptoms and trends toward higher rates of posttraumatic stress symptoms and anxiety symptoms. Parent anxiety was higher with increased time post diagnosis. No demographic or illness-related variables were associated with psychological distress, with the exception of the number of children in the family. 

**CONCLUSIONS:** Parent-child relationships are of fundamental importance during infancy. This study provides novel data highlighting the psychological impact for parents when a cancer diagnosis is made during this critical developmental period, including the contribution of family structure to parental distress. Results provide further support for applying a traumatic stress framework when exploring parent experiences of pediatric cancer. Copyright (c) 2016 John Wiley & Sons, Ltd.


**PURPOSE:** The cancer experience may cultivate positive psychological changes that can help reduce distress during adult survivors of childhood and adolescent cancer life course. The aim of this study is to examine the positive impact of cancer in adult survivors utilizing posttraumatic growth as a guiding framework. 

**METHOD:** Participants were identified and recruited through the Utah Cancer Registry. Eligible cases were diagnosed with cancer age $\leq20$ years from 1973 to 2009, born in Utah, and were age $\geq18$ at study. Semi-structured phone interviews ($N = 53$) were analyzed using deductive analysis. 

**RESULTS:** The primary five themes that emerged were similar to Tedeschi and Calhoun’s (1996) themes for measuring positive effects, and were used to frame our results. The primary themes along with uniquely identified sub-themes are the following: personal strength (psychological confidence, emotional maturity), improved relationship with others (family intimacy, empathy for others), new possibilities (having passion work with cancer), appreciation for life (reprioritization), and spiritual development (strengthened spiritual beliefs, participating in religious rituals and activities). 

**CONCLUSIONS:** For survivors, cancer was life altering and for many the experience continues. Understanding survivors’ complex cancer experience can help improve psychosocial oncology care.


Long and complicated grief is a relevant factor contributing to the deterioration of the older adults’ later life quality. In China, the unintentional consequence of the one-child policy has emerged. There, the group of older adults who lost their only child is called shiduers. The current study compared 42 older adults who lost their only child to 33 older adults who have a child, in term of their physical and mental
health, and social support. The results confirmed the general deteriorating trend in those aspects of the bereaved Chinese parents' life after their only child's death. The results also revealed the impairments on the shiduers' physical, mental, and social aspects were significant, compared to the clinical diagnosis cutoff points used in Western countries. Unique policy and cultural characteristics are the main factors contributing to the severe impairment of shiduers. Results have implications for policy advocacy and practice intervention in specific cultural environments.

Providing services for children and families


The inability of the most vulnerable people to get the care they deserve, whether at the beginning, middle or end of their lives, is a sad reflection on the society’s priorities. This is why the news that children’s hospices are facing a funding crisis is a cause for huge concern. https://www.ncbi.nlm.nih.gov/pubmed/27927109


The RCN has backed a campaign for statutory funding of children’s palliative care services. https://www.ncbi.nlm.nih.gov/pubmed/28395613


Understanding parents’ experience of care is essential to develop high-quality perinatal bereavement services. This study aimed at developing a questionnaire to identify parents’ needs and record their experience of care. The patient experience questionnaire was developed by professionals and parents, and piloted in a tertiary maternity unit. Responses were received from 58 parents. Sensitivity and kindness of staff and time spent with their baby were ranked as ‘very important’ by 95% of parents. Care in these areas largely met their needs (90%), although 5% of respondents stated that partners could have been more involved. Between 8% and 15% of respondents did not feel that language used at the diagnosis of fetal death was sensitive, clear and unambiguous. Parents did not always receive written information about their care (5%) or post-mortem (13%). Analysis of bereaved parents’ responses identified areas for improvement including greater involvement of partners and a need for timely information. Impact statement What is already known on this subject?: Good quality bereavement care after perinatal death reduces the negative emotional, psychological and social effects for parents. Description of parents' experiences is a potential means to improve the quality of perinatal bereavement care. What do the results of this study add?: Parents' needs and experiences of care after perinatal death were recorded using a patient-experience questionnaire designed by a multi-professional team and parents. Staff behaviour, particularly sensitivity and kindness was highly valued by parents. Giving both verbal and written information could be improved. Training is needed for professionals, particularly those who come into contact with bereaved parents less frequently. What are the implications of these findings for clinical practice and/or further research?: Description of parents’ priorities and views can be used to identify areas for improvement in perinatal bereavement care. Parents' views should be regularly sought and used to develop local services in an iterative process. https://www.ncbi.nlm.nih.gov/pubmed/28635351


Cancer is a global health problem particularly in developing countries where the burden of cancer is ever increasing and claiming the lives of about 100,000 children under the age of 15 years every year. Majority of these occur in the Low and Middle Income Countries (LMICs) where 90% of world children live.
Contributing factors to this trend is the reduction of communicable diseases and emergence of new infections, improvement of nutrition and socio-economic conditions, industrialization and urbanization. However, due to its complexity, childhood cancer is given the least priority by the governments’ funding. The weak health systems, poor and late access to diagnosis and care, fewer numbers of trained health care professionals and lack of cancer drugs are amongst the many challenges faced. A major challenge for the future is extending the work to reach the many children who die without access to cancer treatment and palliation. Given the inequalities in the survival rates of children with cancer there is therefore an urgent need to close the gap between developed and developing countries. Strategies at individual, institutional, country, regional and global levels must be implemented to improve cancer survival and its effects on human suffering. These strategies are able to strengthen the health systems, improve care and research, increase awareness and coordinate training of professionals thus meeting the challenges. Financial support should be an integral part of the strategy as the cost of drugs is often a substantial barrier to treatment of cancer in poor countries. However, in resource-limited settings without specialized services, much can still be done to support and offer curative and palliative treatment. As have been shown for several cancers, life can be extended with low-tech treatment protocols which are effective at the same time, decrease sepsis and toxicity. The concept of twinning with privileged nations is paramount to the success of any national cancer program. International partnership offers the opportunity to provide expertise, advice, support and transfer technology from established pediatric oncology unit. Their mission is to build capacity for cancer treatment and research with a vision of developing network of dedicated advocates. The LMIC teams must locally drive projects and volunteers and funding organizations can help to make progress possible. This will require a tremendous effort on the part of both high and low-middle-income countries, if we are all to work together to achieve this goal.


OBJECTIVE AND BACKGROUND: Few previous studies have explored how pediatric palliative care (PPC) influences hospital utilization. We evaluated this among PPC recipients in a single center. METHODS: This is a retrospective cohort study of 109 patients >/=2 years of age who received PPC consultation at a large quaternary children’s hospital from April 2009 to September 2010. We assessed frequencies of hospital admissions and emergency department (ED) visits, use of intensive interventions, and hospital costs. Generalized estimating equations were used to compare outcomes in the two years before and after PPC consultation, stratifying by whether a patient survived two or more years following PPC enrollment. RESULTS: Median age at PPC consultation was 13 years (interquartile range 6-18); 56.0% were male (n = 61), 69.7% white non-Hispanic (n = 76). Fifty-nine percent (n = 64) of patients died during the study period. Overall, annual hospital admission rates decreased from 4.6 (95% confidence interval [CI] 4.0-5.4) before PPC consultation to 3.7 (95% CI 3.4-4.4) after (p = 0.025). Annual ED visits decreased from 0.9 (95% CI 0.7-1.2) to 0.6 (95% CI 0.4-0.8) (p = 0.030). Survivors had significantly decreased hospital admissions [rate ratio (RR) 0.57 (95% CI 0.45-0.73), p < 0.001] and ED visits [RR 0.33 (95% CI 0.20-0.54), p < 0.001]. Decedents had increased intensive care unit use (p = 0.029) but decreased operations (p = 0.002); survivors experienced no change in these outcomes after PPC consultation. Hospital costs remained stable for all (p = 0.929). DISCUSSION: PPC involvement may contribute to decreased hospital and ED use, without escalating costs. These outcomes are most evident in survivors. Hence, PPC may have a measurable long-term impact on hospital use in seriously ill children.


OBJECTIVE: Pediatric hospice has been the adoption of several service provision models in highly developed countries such as UK, Germany, Australia or Canada for a few decades, yet it has seldom been the case in the Asian Continent. This study aimed to evaluate the newest challenge for the children with Life-threatening illness (LTI) and described the characteristic of pediatric palliative care at the first pediatric hospice in Japan. METHODS: A retrospective review of all patients at our pediatric hospice in these three years was conducted. Of the 294 cases reviewed, 269 cases were eligible for analysis. RESULTS: We reviewed 269 patients admitted during the first three years. Most patients required intensive medical intervention. Patients were hospitalized in our pediatric hospice not only for end-of-life care (EOL), but also for respite care. Only 7% of the patients were with cancer. To support children and family to make the most of their time together, we provided a range of medical and recreational care. It is expected that the pediatric hospice will extend and establish cooperation with other hospitals or community services. CONCLUSION: Three years' experience of pediatric palliative care at the first pediatric hospice in the Asian Continent is encouraging. Further experience and improved communication with other pediatric service providers as well as their education in palliative care will enhance the recognition of the capacity of our hospice and support the needs of more children. Furthermore, we would like to introduce the idea of pediatric hospice and spread it throughout the Asian Continent in the future.


This article describes the implementation and evaluation of a new partnership between a children’s hospice service and an NHS children’s community nursing team to support children’s palliative care in the community. Aims and outcomes of the service were established in its initial design and it was monitored for quality and improvement over its first year. Mixed methods of audit and evaluation strategies were used to assess the quality of the service. Findings demonstrate that it has offered significant support to children, and families valued the role of the new Alexander’s nurse. Professionals described improved communication and working relationships through the collaborative partnership. The evaluation also identified areas of learning for future development of the service.


OBJECTIVE: The death of a child from cancer is an intense and life-changing loss for a parent. Guided by the principles of patient- and family-centered care, hospital-based caregivers developed a program to provide bereavement support for parents through phone calls and mailings. The aim of the present qualitative phenomenological study was to understand how parents experienced participating in this bereavement program. METHOD: A total of eight parents from six families participated in a focus-group evaluation of the two-year hospital-based bereavement program. Two social work clinicians/researchers independently analyzed the transcript of the focus group to define themes. RESULTS: Four themes were identified: (1) lived experience of grief, (2) importance of relationships with the hospital-based team, (3) bereavement support from hospital-based providers, and (4) extending bereavement care. SIGNIFICANCE OF RESULTS: Participants indicated the value of ongoing communication and connection with members of the healthcare team, who were often central to a family’s life for years during their child’s cancer treatment. Parents also provided suggestions for extending bereavement support through continued contact with providers and informal annual gatherings, as well as through a peer (parent-to-parent) support program.


Every child with a life-limiting or threatening illness, and his or her family, has a right to palliative care. Palliative care is not limited to end-of-life care, but starts from the moment of diagnosis and is independent of whether there are curative options. To optimise quality of life of both the child and the family, the emphasis of care should be on both somatic and psychosocial and spiritual aspects from the very start, and goals should be set together with the child and the family. A multidisciplinary and proactive approach is essential if this is to be achieved. It is, therefore, strongly recommended that at least every academic hospital should have a multidisciplinary paediatric palliative care team.


Spinal muscular atrophy (SMA) is one of the leading genetic causes of infant death worldwide. However, due to a lack of treatments, SMA has historically fallen short of Wilson-Jungner criteria. While studies have explored the acceptability of expanded newborn screening to the general public, the views of affected families have been largely overlooked. This is in spite of the potential for direct impacts on them and their unique positioning to consider the value of early diagnosis. We have previously reported data on attitudes toward pre-conception and prenatal genetic screening for SMA among affected families (adults with SMA [n = 82] and family members [n = 255]). Here, using qualitative interview [n = 36] and survey data [n = 337], we report the views of this same cohort toward newborn screening. The majority (70%) of participants were in favor, however, all subgroups (except adults with type II) preferred pre-conception and/or prenatal screening to newborn screening. Key reasons for newborn screening support were: (1) the potential for improved support; (2) the possibility of enrolling pre-symptomatic children on clinical trials. Key reasons for non-support were: (1) concerns about impact on the early experiences of the family; (2) inability to treat. Importantly, participants did not view the potential for inaccurate typing as a significant obstacle to the launch of a population-wide screening program. This study underscores the need to include families affected by genetic diseases within consultations on screening. This is particularly important for conditions such as SMA which challenge traditional screening criteria, and for which new therapeutics are emerging.


OBJECTIVE: To describe the proportion and characteristics of patients with late stage cancer that are and are not receptive to receiving rehabilitation services, and the rationale for their level of interest.

DESIGN: Prospective mixed-methods study. SETTING: Comprehensive cancer center in a quaternary medical center. PARTICIPANTS: Adults with stage IIC or IV non-small cell or extensive stage small cell lung cancer (N=311). INTERVENTIONS: Not applicable. MAIN OUTCOME MEASURES: Telephone-acquired responses to the administration of (1) the Activity Measure for Post Acute Care Computer Adaptive Test (AM-PAC-CAT); (2) numerical rating scales for pain, dyspnea, fatigue, general emotional distress, and distress associated with functional limitations; (3) a query regarding receptivity to receipt of
rehabilitation services, and (4) a query about rationale for nonreceptivity. RESULTS: Overall, 99 (31.8%) of the study’s 311 participants expressed interest in receiving rehabilitation services: 38 at the time of enrollment and an additional 61 during at least 1 subsequent contact. Participants expressing interest were more likely to have a child as primary caregiver (18.18% vs 9.91%, P=.04) and a musculoskeletal comorbidity (42.4% vs 31.6%, P=.05). Function-related distress was highly associated with receptivity, as were lower AM-PAC-CAT scores. Reasons provided for lack of interest in receiving services included a perception of their limited benefit, being too busy, and prioritization below more pressing tasks/concerns. CONCLUSIONS: One-third of patients with late stage lung cancer are likely to be interested in receiving rehabilitation services despite high levels of disability and related distress. These findings suggest that patient misperception of the role of rehabilitation services may be a barrier to improved function and quality of life. Efforts to educate patients on the benefits of rehabilitation and to more formally integrate rehabilitation as part of comprehensive care may curb these missed opportunities.


Paediatric palliative care services have increased both in numbers and capacity around the world in response to the needs of children living with life-limiting conditions. Members of the Asia Pacific Hospice Network, who render care to children, have increasingly realised the need to map existing services for enhanced collaborative, educational and advocacy efforts. An online survey was conducted over 2 months among professionals in the region to document current service provision, and at the same time to explore individual training needs and practice challenges. A questionnaire crafted through consensus by members of a new special interest group within the network was used to collect data. 59 distinct responses from 16 countries were obtained to build a directory, which has already been circulated. Content analyses of narrative responses yield further findings. Half of these services catered to adults as well as to children. Staffing and service provision varied across the region but most members worked in teams consisting of multidisciplinary professionals. Numerous service and funding models were found, reflecting wide differences in local conditions and responses to diverse patient populations unique to paediatric palliative care. The highest training needs centred around bereavement and spiritual care. Capacity and funding issues were expected, but significant lack of support by paediatricians was found to be alarming and warrants further study. Amid the heterogeneity, these services share common struggles and face similar needs. Identifying individual profiles of different services potentially helps to draw everyone together, towards a common vision, and towards creating opportunities for sharing of expertise and experience.


SMA is a rare hereditary neuromuscular disease that causes weakness and muscle wasting as a result of the loss of spinal motor neurons. In its most severe form, SMA is the commonest genetic cause of death in infants, and children with less severe forms of SMA face the prospect of lifelong disability from progressive muscle wasting, loss of mobility and limb weakness. The initial discovery of the defective gene has been followed by major advances in our understanding of the genetic, cellular and molecular basis of SMA, providing the foundation for a range of approaches to treatment, including gene therapy, antisense oligonucleotide treatments and more traditional drug-based approaches to slow or halt disease progression. The approval by the US Food and Drug Administration (FDA) of Spinraza (nusinersen), the first targeted treatment for spinal muscular atrophy (SMA), is a historic moment. Disease-focused research charities, such as The SMA Trust (UK), continue to have a crucial role in promoting the development of additional treatments for SMA, both by funding translational research and by promoting links between researchers, people living with SMA and other stakeholders, including
pharmaceutical companies and healthcare providers. Gene Therapy advance online publication, 22 June 2017; doi:10.1038/gt.2017.47. 


Trisomy 13 typically denotes an overall poor prognosis in the setting of multisystem anomalies. Through a provider and parent perspective, this case illustrates the benefit of hope, communication, and teamwork through the integration of a palliative care team in the care of a medically complex child with trisomy 13, resulting in enhanced survival and perceived quality of life for patient and family. (c) 2016 Wiley Periodicals, Inc. 


With the growing number of children and young people with complex care needs or life-limiting conditions, alternative routes for nutrition have been established (such as gastrostomy feeding). The conditions of children and young people who require such feeding are diverse but could relate to problems with swallowing (dysphagia), digestive disorders or neurological/muscular disorders. However, the use of a blended diet as an alternative to prescribed formula feeds for children fed via a gastrostomy is a contentious issue for clinicians and researchers. From a rapid review of the literature, we identify that current evidence falls into three categories: (1) those who feel that the use of a blended diet is unsafe and substandard; (2) those who see benefits of such a diet as an alternative in particular circumstances (eg, to reduce constipation) and (3) those who see merit in the blended diet but are cautious to proclaim potential benefits due to the lack of clinical research. There may be some benefits to using blended diets, although concerns around safety, nutrition and practical issues remain. 


The "patients' rights and end-of-life care" act, known as the Leonetti law, has allowed implementation of palliative care in neonatology as an alternative to unreasonable therapeutic interventions. A palliative care project can be offered to newborns suffering from intractable diseases. It must be focused on the newborn's quality of life and comfort and on family support. Palliative care for newborns can be provided in the delivery room, in the neonatal unit, and also at home. Going home is possible but requires medical support. Here we describe the potential benefits of the intervention of a regional team of pediatric palliative care for newborns, both in the hospital and at home. Two clinical situations of palliative care at home started in the neonatal period and the neonatal unit are presented. They are completed by a retrospective national survey focusing on the type of support to newborns in palliative care in 2014, which was conducted in 22 French regional pediatric palliative care teams. It shows that 26 newborns benefited from this support at home in 2014. Sixteen infants were born after a pregnancy with a palliative care birth plan and ten entered palliative care after a decision to limit life-sustaining treatments. Twelve of them returned home before the 20th day of life. Sixteen infants died, six of them at home. The regional pediatric palliative care team first receives in-hospital interventions: providing support for ethical reflection in the development of the infant's life project, meeting with the child and its family, helping organize the care pathway to return home. When the child is at home, the regional pediatric palliative care team can support the caregiver involved, provide home visits to continue the clinical monitoring of the infant, and
accompany the family. The follow-up of the bereavement and the analysis of the practices with caregivers are also part of its tasks.


Perinatal palliative care allows for an active partnership among a pregnant woman, her family, and her multidisciplinary treatment team and addresses her specialized medical care, emotional, social, and familial needs when a life-limiting fetal diagnosis is confirmed. The purpose of this article is to highlight the multidisciplinary care model used within a perinatal palliative care program. A case study provides a unique perspective on support needed for parents who anticipate that their newborn may die before or shortly after birth.


BACKGROUND: Evidence on the impact of pediatric palliative care programs (PPCP) on resource utilization is scarce and requires broader measures to include utilization beyond the hospital setting. OBJECTIVE: This research aims to provide a Canadian comparative analysis between children in a PPCP with those under usual care, including hospice use to inpatient resource use measurement. METHODS: We conducted a retrospective matched-pairs (disease and age at death) cohort comparison of children who died in hospice versus hospital (never enrolled in a PPCP), from 2008 to 2012. Utilization was retrieved from administrative databases and chart review. The main outcomes were number of admissions and length of stay (LOS). RESULTS: Eleven pairs were found. PPCP users were more likely to have advanced directives (100% vs. 27%). After controlling for disease and age, we found no significant difference in number of admissions; however, PPCP users had an increase in admissions post-referral compared to pre-referral (median 3.08 admissions), driven by the need for critical care. We did not find a significant difference in LOS, but observed longer admissions among PPCP users pre- (1.91 days/month) and post-referral (3.66 days/month) compared to usual care. Over 60% of inpatient utilization shifted to the hospice post-referral. DISCUSSION: The terminal pediatric population referred to PPCP may systematically differ from those under usual care even before enrollment, presenting with higher inpatient utilization in critical care nearing death. A significant portion of inpatient utilization shifted to the hospice, with implications for resource reallocation and enhancements in PPCP referrals.


Ana Todorovic's baby, Nadia, died just before birth. Ana says she received excellent care and was told when 37 weeks pregnant that Nadia was not going to survive for long.


BACKGROUND: Although child mortality is decreasing, more than half of all deaths in childhood occur in children with a life-limiting condition whose death may be expected. AIM: To assess trends in place of death and identify characteristics of children who died in the community after discharge from paediatric intensive care unit. DESIGN: National data linkage study. SETTING/PARTICIPANTS: All children resident
in England and Wales when admitted to a paediatric intensive care unit in the United Kingdom (1 January 2004 and 31 December 2014) were identified in the Paediatric Intensive Care Audit Network dataset. Linkage to death certificate data was available up to the end of 2014. Place of death was categorised as hospital (hospital or paediatric intensive care unit) or community (hospice, home or other) for multivariable logistic modelling. RESULTS: The cohort consisted of 110,328 individuals. In all, 7709 deaths occurred after first discharge from paediatric intensive care unit. Among children dying, the percentage in-hospital at the time of death decreased from 83.8% in 2004 to 68.1% in 2014; 852 (0.8%) of children were discharged to palliative care. Children discharged to palliative care were eight times more likely to die in the community than children who died and had not been discharged to palliative care (odds ratio = 8.06 (95% confidence interval = 6.50-10.01)). CONCLUSIONS: The proportion of children dying in hospital is decreasing, but a large proportion of children dying after discharge from paediatric intensive care unit continue to die in hospital. The involvement of palliative care at the point of discharge has the potential to offer choice around place of care and death for these children and families.


INTRODUCTION: The creation of paediatric palliative care units (PPCU) could optimise the management of children with palliative focus after admission to a paediatric intensive care unit (PICU). This study describes the clinical and epidemiological characteristics of children referred from PICU to the UCPP of the Autonomous Community of Madrid (CAM). The overall treatment, relapses, re-admissions, and deaths, if occurred, are described. PATIENTS AND METHOD: A retrospective review was performed using the medical records from children transferred from the CAM paediatric intensive care units to the paediatric palliative care unit (1 March 2008-31 January 2015). RESULTS: A total of 41 patients were included (26 male/15 female) with a median age of 33 months (range 1-228). In the follow by the UCPP follow-up, the main approaches were respiratory (invasive ventilation with tracheostomy tube 8/41), nutritional (gastrostomy in 20/41), and pharmacological (anti-epileptics in 29/41 and 34/41 on antibiotic treatment). Hospital re-admission was required by 11/41 patients, with no re-admissions to PICU. Of the 13/41 patients who died, 9/13 was at home, with all of them accompanied by the primary caregivers and family, and only 1/9 with the presence of the home team. CONCLUSIONS: The palliative approach at home is feasible in children, and the integration of UCPP could optimise the comprehensive care of previously critically ill children. It is necessary to achieve an optimal domiciliary care should be achieved, and not just because of patient death. More observational, multicentre and prospective studies are needed to confirm these findings.


AIM: End-of-life care remains part of the scope of practice in all neonatal units. This study aimed to characterise the end-of-life care provided in an Australian tertiary neonatal centre, where paediatric palliative care was accessible via a consultative service. METHODS: This retrospective cohort study examined indicators of quality palliative care provided to 46 infants born within a 30-month period. The cohort included four infants who received palliative care consultations additional to usual neonatal care. The care provided was characterised using descriptive statistics. RESULTS: The most common causes of death were congenital abnormality (37%) and complications of extreme prematurity (22%). Very high
proportions of infants and families had family meetings (100%), social worker involvement (100%), memory-making opportunities (100%) and discussion of autopsy (91%). Opiates were prescribed to 76% in the last day of life; most (89%) were administered intravenously. For those prescribed opiates, the median parenteral morphine daily equivalent was 290 mcg/kg/day (interquartile range = 317) in the last 24 h of life. Antenatal resuscitation planning for families of a fetus with a prenatal diagnosis (9%), discussion of preferred location of death (9%), verbal communication with general practitioners (15%) and access to specialised bereavement care (3%) were infrequently provided. CONCLUSIONS: At the time of this study, the neonatal unit was not meeting all of the end-of-life care needs of infants and their families. Care was generally more comprehensive when the palliative care service was consulted.


Background As part of the 2007 health reform in Germany the structure of outpatient palliative care for children and adolescents was adopted for the first time and then implemented in Erlangen-Nuremberg in 2009. Methods The introduction of Pediatric Palliative Home Care (PPHC) at the Hospital for Children and Adolescents at the University of Erlangen-Nuremberg was retrospectively analyzed between the years 2009 to 2014. Referring medical records (paper-based and electronic) were evaluated systematically. Results Considering 69 patients within this study, 44 (63.8%) died during the investigated period and 61% of these Patients deceased at home. 60 patients (87%) had a written emergency plan, which was jointly developed with patients and particularly their parents and relatives in cooperation with the PPHC team. Over the years and with increasing experience, the number and duration of emergency hospitalization decreased. Even complex therapies, such as patient-controlled analgesia with PCA pump could be implemented on an outpatient basis. Conclusion The descriptive cohort study demonstrates that palliative care for children, despite the medical and structural complexity is possible in an ambulatory setting. It allows a similar, if not better care, compared to inpatient palliative care for children and adolescents, not only for the affected patients, but also for their families.


Appropriate respite care for children with life-limiting conditions (LLC) and their families is the cornerstone of high quality paediatric care. The effect of caring for children with LLC on families, including parental needs, cannot be underestimated and respite can give families support while caring for their children. There are many different types of respite care available in Ireland, including specialist respite, inhome respite or out-of-home respite; the wishes of the family should be sought when arranging care. Comparisons between Ireland and the UK have drawn similarities in the benefits and limitations of respite care. Although there are many positive attributes associated with respite care, there are inconsistencies between best practice recommendations and reality. Worldwide issues remain with a lack of funding for respite care. Such care should become an area which attracts funding for future research to improve the quality of life for these children.


OBJECTIVES: Anticipating case management is considered crucial in pediatric palliative care. In 2012, our children’s university hospital initiated a specialized pediatric palliative care team (PPCT) to deliver inbound and outbound case management for children with life-shortening disease. The aim of this report
is to gain insight in the first 9 months of this PPCT. METHODS: Aspects of care during the first 9 months of the PPCT are presented, and comparison is made between patients with malignant disease (MD) and nonmalignant disease (NMD) in a retrospective study design. Insight in the aspects of care of all patients with a life-shortening disease was retrieved from web-based files and the hour registrations from the PPCT. RESULTS: Forty-three children were supported by the PPCT during the first 9 months: 22 with MD with a median of 50 (1-267) days and 29 minutes (4-615) of case management per patient per day and 21 patients with NMD with a median of 79.5 (5-211) days and 16 minutes of case management per day (6-64). Our data show significantly more interprofessional contacts for patients with MD and more in-hospital contacts for patients with NMD. The median number of admission days per patient was 11 (0-22) for MD (44% for anticancer therapy) and 44 (0-303) for NMD (36% for infectious diseases). SIGNIFICANCE OF RESULTS: This overview of aspects of pediatric palliative care management shows shorter but more intensive case management for MD in comparison with NMD. This insight in palliative care management guides the design of a PPCT.


BACKGROUND: Case management is a subject of interest within pediatric palliative care. Detailed descriptions of the content of this type of case management are lacking. We aim to describe the contents of care provided, utilization of different disciplines, and times of usage of a pediatric palliative care case management program compared for patients with malignant disease (MD) and non-malignant disease (NMD). METHODS: A three-month prospective study, with questionnaires filled in by members of a pediatric palliative care team (PPCT) for each contact with parents. RESULTS: Four hundred fifty-five contacts took place with parents of 70 patients (27MD, 43NMD). Sixty-two percent of all contacts were with the specialized nurse. The child life specialists, psychologist and social worker were also regularly consulted, the chaplain was not consulted. Ninety-five percent of all contacts took place between 8 am and 6 pm during weekdays, a limited number between 6 pm and 9 pm. Twenty-five percent of all contacts were proactively initiated by the PPCT, 25 % were initiated by parents. In these care characteristics, no differences were seen for MD and NMD patients. Psychosocial topics were addressed most frequently. MD patients consulted the PPCT more often about school and NMD patients about socio-economic issues. CONCLUSIONS: All different disciplines of the PPCT were regularly consulted, except for the chaplain. With an easy accessible team with a highly pro-active approach, availability from 8 am to 9 pm seems sufficient to accommodate patient’s and parent’s needs. More anticipation seems required for socio-economic topics. This insight in pediatric palliative care management can provide guidance in the development of a new PPCT.


Funding for children’s hospices and palliative care charities in England is in crisis with seriously ill children facing a postcode lottery for their care, a new report has revealed.


AIM: Prior to July 2013, a solo medical specialist provided a pain management service 1.5-2 days/week to children and young people aged 0-19 years, and their families at John Hunter Children’s Hospital, Newcastle, NSW. A new multidisciplinary children’s complex pain team now continues that service. This study aimed to identify the demographic and clinical characteristics of children, young people and their
families referred to a paediatric pain specialist in the 5.5 years prior to the establishment of a multidisciplinary service and to quantify anecdotal observations, determine service priorities and identify clinical improvement opportunities. METHODS: A retrospective review of the medical records of all new patients seen between January 2008 and June 2013 was conducted. Data sets for patient demographics, clinical characteristics, service outputs and disposition at discharge were determined prior to data extraction. RESULTS: A total of 114 children and young people aged between 7 days and 18 years (mean +/- SD = 12.54 +/- 3.6 years) were consecutively referred to the service. Many demographics are consistent with those previously reported; however, the number of children who identified as being of Aboriginal origin (11%), with rare diseases (28%), new diagnoses made (47%), child protection reports submitted (14%) and psychological morbidity in children (58%) and caregivers (38%) are new findings in the context of pain management and serve as indicators of the complex service needs of these patients and their families. CONCLUSION: The complexities encountered in this small cohort provide an indication of the time investment needed to understand and manage complex paediatric pain, especially in the contexts of complex families, time-poor general practitioners and under-resourced communities.


CONTEXT: California implemented pediatric palliative care legislations that allowed children to receive curative and supportive care from diagnosis of a life-threatening serious illness in 2010. Palliative care policies may improve access to hospice care as children near end of life. OBJECTIVES: The aim of this study was to examine the effect of the palliative care policy on hospice utilization for children and their families was investigated. METHODS: Using 2007 and 2010 California Medicaid data, a difference-in-difference analysis was conducted to analyze hospice use (i.e., hospice enrollment, hospice length of stay) changes for children who resided in pediatric policy counties relative to those who did not. The sample of children in California who died with a life-threatening serious illness in 2007 and 2010 equaled 979 children. RESULTS: More than 10% of children enrolled in hospice care with an average of less than 3 days of hospice care. The palliative care policy did not have any effect on hospice enrollment. However, the policy was positively associated with increasing days in hospice care (incidence rate ratio = 5.61, P < 0.05). The rate of hospice length of stay increased by a factor of 5.61 for children in palliative care counties compared with children unaffected by the policy. CONCLUSION: The pediatric palliative care policy was associated with longer lengths of stay in hospice once the children were enrolled. Policies promoting palliative care are critical to ensuring access to hospice care for children.


Over 42,000 children die each year in the United States, including those with intellectual disability (ID). Survival is often reduced when children with intellectual disability also suffer from significant motor dysfunction, progressive congenital conditions, and comorbidities. Yet, little is known about hospice care for children with intellectual disability. The purpose of this study was to explore the relationship between intellectual disability and hospice utilization. Additionally, we explored whether intellectual disability combined with motor dysfunction, progressive congenital conditions, and comorbidities influenced pediatric hospice utilization. Using a retrospective cohort design and data from the 2009 to 2010 California Medicaid claims files, we conducted a multivariate analysis of hospice utilization. This study shows that intellectual disability was negatively related to hospice enrollment and length of stay. We also found that when children had both intellectual disability and comorbidities, there was a positive association with enrolling in hospice care. A number of clinical implications can be drawn from the study findings that hospice and palliative care nurses use to improve their clinical practice of caring for children with ID and their families at end of life.

BACKGROUND: Hospice care for children with multiple complex chronic conditions (MCCC) is complicated given their unique health at the end of life (EOL). Little is known about the quality of the hospice care MCCC children receive and how that might differ from children without MCCC.

OBJECTIVE: To compare the quality of hospice care (i.e., structures, processes, outcomes) between children with and without MCCC.

METHODS: This retrospective, comparative study used data from the National Home and Hospice Care Survey, which included a nationally representative sample of paediatric hospice patients. The Pearson chi-square and Wald tests for comparisons were used.

RESULTS: MCCC children enrolled in hospice care for over 2 months with multiple visits by hospice staff. They had low symptom burden with minimal discontinuity of care at EOL. Children without MCCC had short length of stays in hospice with few visits by nurses and other clinicians. These children had high symptom burden and significant disenrollment from hospice care to receive more aggressive treatment.

CONCLUSIONS: The findings revealed significant differences in paediatric hospice care between MCCC and non-MCCC children, which provides critical insight into the quality of hospice care.


OBJECTIVES: To examine the relationship between pediatric primary care involvement and hospice and home health care use at end of life.

METHODS: California Medicaid data were used to estimate the relationship between pediatric primary care involvement and use of hospice and home health care using generalized estimating equations.

RESULTS: Of the 2037 children who died between 2007 and 2010, 11% used hospice and 23% used home health. Among all children, primary care was not related to hospice use and was associated with home health use, usual source of care (OR = 1.83, P < .05), comprehensive care (OR = 1.60, P < .05), and continuous care (low: OR = 1.49, P < .05; moderate: OR = 2.57, P < .05; high: OR = 2.12, P < .05). Primary care for children aged 15 to 20 years was related to hospice use, usual source of care (OR = 4.06, P < .05) and continuous care (low: OR = 4.92, P < .05; moderate OR = 4.09, P < .05; high OR = 3.92, P < .05). Primary care for children under 5 years was associated with home health use, usual source of care (OR = 2.59, P < .05), comprehensive care (OR = 2.49, P < .05), and continuous care (low: OR = 2.22, P < .05; moderate: OR = 3.64, P < .05; high: OR = 3.62, P < .05). For children aged 6 to 14 years, this association was seen with continuous care (moderate: OR = 2.38, P < .05; high: OR = 2.13, P < .05). Home health for children aged 15 to 20 years was related to continuous care (moderate: OR = 2.32, P < .05). CONCLUSION: Primary care involvement affected hospice use among older age-groups and home health use among younger age-groups. These findings underscore the need for clinical knowledge about end-of-life care for children of all ages among primary care providers.


INTRODUCTION: More than 8,000 Hispanic children die annually in the United States; yet little is known about the end-of-life care utilized. The purpose of this study was to examine the children and family characteristics associated with end-of-life care for Hispanic children.

METHOD: A sample of 370 Hispanic children was created, using the 2009-2010 California Medicaid data. The relationship between child and family characteristics and end-of-life care utilization (i.e., hospice enrollment, emergency room utilization, hospital admissions) was analyzed using multivariate regression.

RESULTS: Pediatric hospice accessibility (p < .05), palliative care policy (p < .01), congenital anomalies (p < .01), and cardiovascular conditions (p < .01) were related to hospice enrollment. Usual source of care (p < .001), functional status (p < .001), palliative care policy (p < .01), and private insurance (p < .01) were associated with emergency room utilization, while usual source of care (p < .001), cancer (p < .001), and disability status...

This article explores the 2014 Institute of Medicines recommendation concerning primary palliative care as integral to all neonates and their families in the intensive care setting. We review trends in neonatology and barriers to implementing palliative care in intensive care settings. Neonatal primary palliative care education should address the unique needs of neonates and their families. The neonatal intensive care unit needs a mixed model of palliative care, where the neonatal team provides primary palliative care and the palliative subspecialist consults for more complex or refractory situations that exceed the primary teams skills or available time.


PURPOSE OF REVIEW: A significant number of newborns are affected by life-limiting or life-threatening conditions. When prolongation of survival is no longer a goal, or prognosis is uncertain, a plan of care focused on the infant’s comfort is essential. The aim of this article is to review the most recent and relevant literature regarding neonatal palliative care (NPC). RECENT FINDINGS: A variety of perinatal and NPC programs are described, but most programs focus exclusively on end-of-life care. Moreover, there is a great need to standardize practices and obtain follow-up quality measures. Guidelines to address infants’ basic needs, to achieve a state of comfort, are proposed. A multidisciplinary team addressing the infants’ medical and nonmedical needs, parental grieving process, and providers’ distress is recommended. SUMMARY: NPC is a unique multidisciplinary approach for the care of newborns affected by life-limiting or complex medical conditions with uncertain prognosis. Standardized guidelines should be implemented with the goal of achieving a state of comfort for newborns throughout the course of illness. Further studies are warranted to assess whether NPC effectively promotes newborns' comfort and parents and providers' satisfaction.


BACKGROUND: Approximately 25% of hospice disenrollments in the United States occur as the result of hospitalization, which can lead to burdensome transitions and undesired care. Informal caregivers (e.g., spouses, children) play a critical role in caring for patients on home hospice. Research examining hospital-related disenrollment among these patients is limited. OBJECTIVE: To understand the events surrounding the hospitalization of patients discharged from home hospice through the perspective of their informal caregivers. DESIGN: Thirty-eight semistructured phone interviews with caregivers were conducted, and data regarding the events leading to hospitalization and hospice disenrollment were collected. Study data were analyzed by using qualitative methods. SETTING/SUBJECTS: Subjects included caregivers of 38 patients who received services from one not-for-profit home hospice organization in New York City. Participants were English speaking only. MEASUREMENTS: Caregiver recordings were transcribed and analyzed by using content analysis. RESULTS: Content analysis revealed four major themes contributing to hospitalization: (1) distressing/difficult-to-witness signs and symptoms, (2) needing palliative interventions not deliverable in the home setting, (3) preference to be cared for by nonhospice physicians or at a local hospital, and (4) caregivers not comfortable with the death of their care recipient at home. Over half of all caregivers called 911 before calling hospice. CONCLUSIONS: Our study provides insight into the events leading to hospitalization of home hospice patients from the caregivers’ perspective. Further research is needed to quantify the drivers of
hospitalization and to develop interventions that reduce utilization, while improving care for home hospice patients and their caregivers.


Neonates with chronic respiratory failure have uncertain prognosis and can face significant treatment burden. As the trajectory of the illness becomes more concerning, consultation with a pediatric palliative service should be considered, especially as therapeutic options shift from standard to "innovative." Benefits include as follows: supporting emotionally conflicted providers and parents, maintaining transparency in determination of goals, and balancing medical progress with each individual patient’s and family’s best interests.


AIM: This paper reports on parent and professional perspectives of step down care in assisting the transition from hospital to home, within one children’s hospice in a constituent country of the United Kingdom. BACKGROUND: In recent years increasing numbers of children dependent on long term assisted ventilation have been noted. Meeting the complex physical, emotional and social needs of the child and family is challenging. Many of these children spend extended periods in hospital even when medically stable. DESIGN: This was a qualitative study using an inductive, semantic analytic approach within a realist epistemology. METHODS: Data collection was carried out in 2013. Interviews took place with parents (n=5) and focus groups with professionals (n=26) who had experience of step down care. RESULTS/FINDINGS: Multiple benefits of step down in the hospice were clear. Both sets of accounts suggested that for children and families life was 'on hold' in hospital. Hospice was considered a home-like environment where the child and family could 'live again'. Parents reflected that, in hospice they were 'living, not existing' while professionals highlighted hospice as nurturing and empowering the whole family, promoting the child's development while safely meeting their clinical needs. CONCLUSION AND IMPLICATIONS FOR PRACTICE: The study highlights a number of crucial benefits to the child and family both in the immediate and longer terms. The collective perspectives therefore endorse hospice as a potential viable choice for these children and their families during the always difficult, usually protracted transition from hospital to home. This article is protected by copyright. All rights reserved.


BACKGROUND: Palliative care is a holistic framework that is designed to improve quality of life by identifying and treating distressing symptoms of life-threatening or complex conditions. Neonatal palliative care (NPC) has potential benefits for parents, staff, and patients, yet evidence suggests that implementation and utilization of organized NPC services are low. PURPOSE: The purpose of this study is to answer the clinical question: In neonatal intensive care, what evidence can be used to guide implementation of palliative care protocols? SEARCH STRATEGY: A literature search was conducted using CINAHL (Cumulative Index of Nursing and Allied Health Literature), PubMed, and the Cochrane Library databases. Publications with a focus on neonates, neonatal intensive care unit, and implementation or evaluation of a palliative care protocol, team, or educational intervention were retained. RESULTS: The search yielded 17 articles that fit with the following themes: NPC protocols or teams (n = 8), healthcare team needs (n = 3), and barriers to implementation (n = 6). Approaches to NPC implementation were varied, and outcome data were inconsistently reported. Healthcare team members cited a need for education and consistent, ethical delivery of NPC. Common barriers were identified as lack of NPC education, poor communication, and lack of adequate resources such as staff and space. IMPLICATIONS FOR PRACTICE AND RESEARCH: Successful team approaches included standardized
order sets to initiate NPC, NPC education for staff, and references to NPC guidelines or protocols. Barriers such as lack of interdisciplinary cooperation, lack of appropriate physical space, and lack of education should be addressed during program development. Further research priorities for NPC include seeking parent perceptions, shifting focus from mostly end-of-life to an integrated model, and collecting outcome data with rigor and consistency.


Providing end-of-life care to children with cancer is most ideally achieved by initiating palliative care at the time of diagnosis, advocating for supportive care throughout the treatment trajectory, and implementing hospice care during the terminal phase. The guiding principles behind offering palliative care to pediatric oncology patients are the prioritization of providing holistic care and management of disease-based symptoms. Pediatric hematology-oncology nurses and clinicians have a unique responsibility to support the patient and family unit and foster a sense of hope, while also preparing the family for the prognosis and a challenging treatment trajectory that could result in the child’s death. In order to alleviate potential suffering the child may experience, there needs to be an emphasis on supportive care and symptom management. There are barriers to implementing palliative care for children with cancer, including the need to clarify the palliative care philosophy, parental acknowledgement and acceptance of a child’s disease and uncertain future, nursing awareness of services, perception of availability, and a shortage of research guidance. It is important for nurses and clinicians to have a clear understanding of the fundamentals of palliative and end-of-life care for pediatric oncology patients to receive the best care possible.


Perinatal palliative medicine is an emerging subspecialty within paediatric palliative medicine, neonatal medicine, fetal medicine and obstetrics. It comprises patient-focused, non-judgemental shared decision making and aims to provide holistic multidisciplinary support for families. In this paper we define and describe one model for providing perinatal palliative care, drawing on the personal and professional experience of the authors.


AIM: The care of a child with a life-limiting condition proves an emotional, physical and financial strain on the family that provides care for their child. Respite care is one way which allows carers to receive some relief and support in the context of this burden of care. The provision of and the requirements for respite in this context is poorly understood. This survey aims to describe the types of respite care families receive, the respite that they would ideally receive and the barriers that prevent this. METHODS: A cohort of 34 families cared for by the Paediatric Palliative Care Service in Queensland were approached to participate in a 20-question survey about their current respite preferences for future respite, with 20 surveys returned. RESULTS: Three of the families (15%) reported receiving no respite in the previous 12 months. Families who received respite received a combination of formal respite (a structured care provider) and informal respite (family or friends). Ten families (50%) reported that they would want the
time of respite changed. Barriers to receiving adequate respite included complexity of care of the child, financial barriers and lack of a respite provider. CONCLUSIONS: There is disparate provision of respite care with the main perceived barrier to attaining ‘ideal respite’ being the lack of a provider able to meet the complex care needs of their child. The provision of respite across diversity in geography; medical condition; social and cultural needs remains a challenge.


The choice of palliative care can be made today in the perinatal period, as it can be made in children and adults. Palliative care, rather than curative treatment, may be considered in three clinical situations: babies born at the limits of viability, withholding/withdrawing treatments in the NICU, and babies with severe malformations of genetic abnormalities identified during pregnancy. Only the last situation is addressed hereafter. In newborn infants as in older patients, palliative care aims at taking care of the baby and at providing comfort and well-being. The presence of human beings by the newborn infant, most importantly the parents and family, is of utmost importance. The available time should not be used only for care and medical treatments. Sufficient time should be kept for the parents to interact with the baby and for human presence and warmth. The best interests of the newborn infant are the main element for guiding appropriate care. Before birth, the choice of palliative care for newborn infants requires successive steps: (1) establishing a diagnosis of malformation(s) or genetic abnormalities; (2) making a prognosis and ruling out intensive treatments at birth and thereafter; (3) giving the parents appropriate information; (4) assisting the pregnant woman in deciding to continue pregnancy while excluding intensive treatment of the newborn baby; (5) dialoguing with parents about the expected duration of the baby’s life and the related uncertainty; (6) planning of palliative care to be implemented at birth; (7) preparing a plan with the parents for discharging the infant from the hospital and for taking care of him over a long time, when it is deemed possible that the baby may live for more than a few days. https://www.ncbi.nlm.nih.gov/pubmed/28007510


BACKGROUND AND OBJECTIVES: Health care use and cost for children at the end of life is not well documented across the multiple sectors where children receive care. The study objective was to examine demographics, location, cause of death, and health care use and costs over the last year of life for children aged 1 month to 19 years who died in Ontario, Canada. METHODS: We conducted a population-based retrospective cohort study using administrative databases to determine the characteristics of and health care costs by age group and cause of death over a 3-year period from 2010 to 2013. RESULTS: In our cohort of 1620 children, 41.6% died of a chronic disease with wide variation across age groups. The mean health care cost over the last year of life was $78 332 (Canadian) with a median of $18 450, reflecting the impact of high-cost decedents. The mean costs for children with chronic or perinatal/congenital illnesses nearly tripled over the last 4 months of life. The majority of costs (67.0%) were incurred in acute care settings, with 88.0% of children with a perinatal/congenital illness
and 79.7% with a chronic illness dying in acute care. Only 33.4% of children received home care in the last year of life. CONCLUSIONS: Children in Ontario receive the majority of their end-of-life care in acute care settings at a high cost to the health care system. Initiatives to optimize care should focus on early discussion of the goals of care and assessment of whether the care provided fits with these goals. https://www.ncbi.nlm.nih.gov/pubmed/28255066


OBJECTIVES: Pediatric subspecialty care, including multidisciplinary palliative care, tends to be located in urban academic centers or children's hospitals. Telehealth provides the opportunity to care for patients who would otherwise not be able to access services. We present cases wherein telehealth was used to provide counseling services to patients who would not have been able to receive this service. METHODS: We discuss cases of telehealth use for patient and family counseling in the setting of palliative care and bereavement follow-up. Patients who live a great distance from the hospital with limited access to services were followed by a hospital-based pediatric palliative care team. Patients and families gave feedback after use of telehealth for counseling services. RESULTS: Counseling through telehealth by our hospital-based palliative care social worker was successful for all parties involved: patient, family, and social worker. CONCLUSIONS: Telehealth helps relieve disparity in access to services and care, which is particularly problematic in pediatrics and mental health. For the patients in this case series, it was an effective modality to receive counseling services and meet needs that otherwise would not have been addressed. https://www.ncbi.nlm.nih.gov/pubmed/28486031


In Germany, there are about 50,000 children, adolescents and young adults with life threatening or life limiting conditions, who will likely die due to their illness before reaching the age of 40. In recent years prevalence has increased significantly. The aim of paediatric palliative care (PPC) is to optimize quality of life for the child, adolescent or young adult and its whole family. Whenever possible the patient should be treated at home. The very complex and rare diseases as well as the patients' wide range of age and developmental stage are particularly challenging within PPC. Many PPC patients have cognitive disabilities and are not able to communicate verbally. In contrast to adult palliative care, PPC is often delivered for many years. To date, families with a child suffering from a life limiting condition have access to several care systems; however most of them are still financed by donations. One of PPC's most important tasks is the implementation of individual case management to find the right mix of care provision, its flexible adaption on changing needs and the appropriate intensity of care. Specific education and training courses in the field of PPC are still rare. There is a single chair for childrens' pain therapy and paediatric palliative care at Witten/Herdecke University in Germany. In addition, quality-checked multiprofessional PPC courses for the additional "palliative health care professional" designation based on the Dattelner Curriculum are offered at several institutions. https://www.ncbi.nlm.nih.gov/pubmed/27878604