IN THIS ISSUE . . .

Guest editorial
Emotional labour and caring for infants who are not expected to survive
Victoria Kain

Neonatal palliative care nursing: working with infants on the cusp of life – a thematic review
Helen Cooper, Lesley Cuthbertson and Sara Fleming

Prevalence of assigned primary nurses in a neonatal intensive care unit during the period 1998–2007
Johannes van den Berg and Viveca Lindh

New perspectives on the contribution of digital technology and social media use to improve the mental wellbeing of children and young people: a state-of-the-art review
Andrew Clifton, Deborah Goodall, Sasha Ban and Eileen Birks
Neonatal, Paediatric and Child Health Nursing

Volume 16 Number 1 – March 2013

Official journal of the

Australian College of Children & Young People’s Nurses
www.accypn.org.au

Australian College of Neonatal Nurses
www.acnn.org.au

Neonatal Nurses College Aotearoa

Nurses for Children and Young People of Aotearoa

Journal philosophy

The journal is the official publication of Australian and New Zealand professional nursing groups caring for babies, children and their families. The four organisations represent a diversity in nursing, ranging from intensive care nursing to the community-based nursing services, found in cities and remote areas throughout Australia and New Zealand.

The journal will endeavour to reflect this diversity by its content. Neonatal, paediatric and child health nursing have many different aspects that may be relevant to more than one sector of the membership. In addition to clinically oriented material, including research, the journal also provides a forum for articles on professional aspects of nursing that apply to all nurses and in particular to nurses working with babies, children and families.

This journal has a Band 2 JET Ranking from the Australian Council of Deans

Disclaimer: Mention of products in articles or in advertisements in the NPCHN journal does not constitute endorsement by ACCYPN, ACNN, NNCA or NCYPA.
In this issue, Cooper, Cuthbertson and Fleming report the findings of a thematic review depicting the challenges of caring for babies who are not expected to survive. A prevalent theme in this work revolves around the significant emotional burden placed upon the nurses who care for these babies. This emotional component of care can be described in terms of “emotional labour”, a term first coined by Hochschild in 1983. Emotional labour is defined as an ingredient in any kind of occupation where the “object” being cared for, or “worked upon”, is alive, sentient or reacting; or as any labour involved in dealing with another person’s emotions. Emotional labour is a component of all nursing genres to a degree, because nursing involves emotional work impacting upon the nurses’ emotional wellbeing, yet emotional wellbeing is integrally correlated to professional practice.

Cooper et al. eloquently capture the emotional rollercoaster that the neonatal nurse rides on a daily basis: the joy of birth and the overwhelming grief of death, coupled with a prevailing sense of failure and bewilderment. Failure is a notion in itself: a notion of curing at all costs, and it is widely accepted that in acute care settings the purpose of treatment is generally to cure, and it is for this reason that facing the death of a patient and providing palliative care can be “uncomfortable”, and engender a sense of failure.

One has to contemplate the significant impact of emotional labour on the nurse caring for these babies, and whether it is acknowledged as such. In any area of caring for patients at the end of life, a good deal of emotional distress is encountered and, in particular, feelings of loss when a nurse–patient relationship ends. Creating and sustaining these relationships with infants and families should therefore be acknowledged as hard emotional labour. At the heart of the matter is the desire that parent–nurse closeness in the neonatal intensive care unit is desirable; however, the emotional burden of this closeness seems to be seldom documented, or explored in empirical research.

Clearly, this type of nursing practice needs to be recognised by organisations as emotional labour. Emotional labour may result in disenfranchised grief, and caregiver suffering. In my own research, it is reported that experiencing grief and distress when caring for these types of babies may be interpreted by the nurse as a weakness. Given this, neonatal nurses express reluctance in availing themselves of counselling opportunities to address this aspect of their work even when these services are available.

I suggest that developing coping skills to deal with emotional labour, whilst acknowledging grief and sadness, may assuage many of the dilemmas that neonatal nurses experience in caring for these types of babies, including conflict with parents and colleagues when differing opinions manifest.

Neonatal palliative care nursing: working with infants on the cusp of life – a thematic review

Helen Cooper  
Adelaide, SA, Australia

Lesley Cuthbertson  
School of Nursing & Midwifery, Faculty of Health Sciences, Flinders University, Adelaide, SA, Australia

Sara Fleming  
Nurse Practitioner, Paediatric Palliative Care, Women’s and Children’s Hospital, Adelaide, SA, Australia  
sara.fleming@health.sa.gov.au

Abstract

Neonatal palliative care requires personal and professional commitment on behalf of nurses. Technological advances can maintain infants, but when decisions from the beginning of life are about how best to die, the medical, emotional and moral dilemmas are complex. Palliative care should begin when illness is diagnosed and continue regardless of any treatment an infant may receive directed at their illness. Research has shown that while nurses find palliative care rewarding, the emotional effects upon them need further investigation. This thematic review analyses 16 articles to identify nurses’ experience of providing palliative care and to identify potential barriers to managing this care effectively. Findings revealed that nurses felt distressed trying to manage the transition from curative to palliative care for neonates. Nurses expressed ambivalence regarding the use of invasive technology and were concerned with enhancing the quality of life during the period of dying. Experience and education emerged as critical factors when nurses were managing the complexities of palliative care and the emotional wellbeing of nurses was a vital element to enabling comprehensive care for neonates. A palliative care protocol developed by a multidisciplinary team may bring consensus to using such a protocol in the neonatal intensive care unit (NICU). Future research is recommended to focus on the nursing experience of providing palliative care. Nurses working in an NICU develop skills and attributes that may be lost to the profession if their experiences are not sought and validated.

Keywords  Neonatal, paediatric, nursing, palliative care.

What is known about this topic

• Neonatal palliative care requires personal and professional commitment on behalf of the nurses involved.
• While technology can maintain infants on the cusp of life, there are those whose physiologic conditions require medical, emotional and ethical decisions from the beginning of life that are incredibly complex.
• There has not been extensive research into the emotional impact on nursing staff regarding their capacity to provide this care.

What this paper adds

• A major focus has been to understand the role of the nurse in neonatal palliative care. The experience, understanding, empathy and compassion for their work that is developed by nurses may be lost to the profession if their perspective is not sought out and validated.
• To highlight the complex nature of the work undertaken by neonatal nurses in the field of palliative care.

Declarations

Competing interests  None.

Funding  Not applicable.

Ethical approval  Not applicable.

Contributorship  Concept of study – HC; all work and writing – HC, supervised and edited by LC.

Acknowledgements

We wish to thank Dr Lindy King, Associate Dean, Senior Lecturer, School of Nursing and Midwifery, Flinders University and the Flinders University School of Nursing and Midwifery for supporting the 2009 BN Mentoring Project.

Introduction

The provision of palliative care in the adult community has become an established and integral part of contemporary adult heath care. Palliative care for the neonatal and paediatric populations has also become an important part of the care plans developed for infants and children at the end of life. The World Health Organization states that for children this should encompass the palliative care principles of quality of life for those faced with a life-threatening...
illness. This definition embraces the notion that for children palliation also involves providing support for the family and should begin when the illness is diagnosed and continue, regardless of any treatment the child may receive directed at their illness.

Infancy and childhood are generally viewed as the time in life when the future is bright and full of potential. However, many will die each year despite the extraordinary advances in medical practices that can manage illnesses better than ever before. The Australian Bureau of Statistics in the Health of Children in Australia report from 2004–05, reported that most childhood deaths (68%) occurred in the first year of life. However, the survival rate of the most premature of infants has continued to improve as medical technology has progressed. Kelly states that infants born at 23 to 25 weeks' gestation are currently at the edge of viability. While technology can maintain these infants at the very cusp of life, there are those whose physiologic conditions are so serious that decisions from the very beginning of life are centred on how to manage their pathway through appropriate curative treatments to end-of-life care. These infants present their families and the staff who care for them with complex medical, emotional and moral dilemmas. The advances in technology have conditioned society to believe that not only do all infants have a chance at life but that they will survive the tremendous medical challenges they are faced with. However, for some this is not physiologically possible and their parents, families and the staff need to prepare them for death. As Carter reports, these decisions are framed around determining the balance between the benefits and burdens of initiating or continuing life-prolonging treatments.

Palliative care if instituted can aid the pathway to death and throughout this the nursing staff play a critical role. Namasivayam et al. make the point that nurses are considered to be the health care professionals closest to the family during all phases of terminal illness. Their study found that while nurses working in palliative care found this to be an extremely rewarding role, "the emotional drainage experienced by these nurses needs further attention". Palliative Care Australia highlights the differing needs in palliative care when infants and children are the focus. They state that palliative care for this population requires special consideration because the parents have the legal and moral responsibility for care of their child, while trying to manage their own emotional needs. This creates a complex dynamic that is best managed by partnership between specialist paediatric and palliative care services.

The unique role nurses have in the lives of their patients becomes more poignant when considered in the light of working with infants and children. Papadatou reflects on this and believes that the death of a child results in intensified grief reactions, and heightened feelings of sadness and helplessness on behalf of the health professional. Papadatou suggests that this can become a triple failure for the health professional because, firstly, they did not have the skills to save a life, secondly, because as adults they were unable to protect the child from harm, and thirdly, a feeling of having betrayed the parents who had trusted them with their child.

Palliative care has become recognised as having an essential role in paediatric end-of-life care. As Moro et al. report, while palliative care is a viable option for critically ill infants, it is rarely provided as an option for the families. When palliation is a part of the care plan, the role of the nurse has received little attention in the literature. This literature review aims to identify the potential barriers that inhibit nurses when providing palliative care for infants.

Method

The articles for this literature review were found by searching electronic databases including CINAHL (EBSCO), Web of Science, Medline, ProQuest, Journals@Ovid full text and Wiley Interscience (incorporating Blackwell Synergy). The search was conducted using combinations of the keywords neonatal, palliative, nursing, end-of-life, ethical, infant, paediatric/pediatric and oncology. The bibliographic details of articles retrieved initially elicited details for a further three articles along with articles provided by a paediatric palliative care nurse. The articles included were primary, peer-reviewed research articles in English from 1999 to 2009, those with nurses as part of their research population and those that discussed palliative care.

The intention of the review was to research articles that related specifically to the nursing perspective of palliative care in the neonatal period. However, there was limited primary research available and the scope of the review was expanded to research that focused on nursing perspectives in paediatric palliative care and oncology/cancer services where end-of-life care was also a focus. A study was also included that described the implementation of a pre-viability counselling programme for mothers at risk of premature birth. This was considered valuable as it supported the premise that parents, when provided with information that is informative and respectful regarding their infant's prognosis, are able to accept the notion of palliative care, thus enabling early implementation of this form of care. Articles were not included when they related specifically to medical staff and nurses were not a part of the population studied or if the article was an opinion piece or a case study. Overall, 16 primary research articles were selected for inclusion in the review.

Analysis

A number of research methodologies were utilised in the selected articles, including qualitative, quantitative, mixed design and one Delphi technique study. The rigour and credibility of this study was established using frameworks established by Taylor et al., the Critical Appraisal Skills Programme and the University of Salford Evaluation Tool for Quantitative Studies. Of the 16 selected studies, it was noted that nine studies selected sample groups from a single practice setting, thus limiting the generalisability of the findings. Limitations were also generated by the research design itself, such as the...
Delphi study, or because the instrument had not been tested. It is acknowledged that these limitations reduce the reliability and validity of these studies and may limit the generalisability of the findings of this study. This must be taken into account when interpreting the overall findings; however, as primary research into neonatal palliative care remains limited and the studies were found to inform the research question, these studies were included in the review.

The nine qualitative studies reported a number of limitations including the single practice setting as mentioned, low response rate and, in particular, a self-selection bias. While this limits the generalisability of the findings, the nature of the phenomenon being studied was focused on investigating attitudes, practices and needs of the neonatal and paediatric populations in relation to palliative care. This allows a more flexible approach to the investigation and the studies were able to provide a better understanding of the nature of the work in these areas and thus prompt further research. Taylor et al. note that qualitative research is used to explore the changing nature of knowledge and builds from the “ground up” to make larger statements about what is being investigated. The nursing perspective in neonatal palliative care is an emerging field of research and the qualitative data being obtained has much to offer with new and revised knowledge, as it provides rich descriptions of context, lived experience and potential for change10.

The five quantitative studies use questionnaires or surveys to obtain their data. Taylor et al. state that the use of self-report in this manner, as a method of obtaining data, can be disadvantageous for a number of reasons including a low return rate and misinterpretations that cannot be accounted for. These were acknowledged by the studies themselves; however, despite this, because the population being studied is a defined one, the sample used by a study could be considered to be indicative of the population. This also relates to the qualitative studies using similar data collection techniques. These studies reported similar limitations with their data as the qualitative studies, including low response rate and selection bias. While this limits the applicability and generalisability of the findings for all but one of the studies13, the findings from these studies provide impetus for further research in neonatal palliative care. This point will be expanded upon later in this section.

One of the studies used the Delphi survey technique, a means of obtaining a range of expert opinions on a topic without actually meeting the participants10. This format enabled Catlin and Carter14 to access a large number of expert people over a wide geographic area, enabling consensus over time on their design for a palliative care protocol. The construct of the Delphi technique relies upon identifying a wide range of experts to administer an anonymous questionnaire10. Catlin and Carter14 identified a wide range of experts to survey and managed the limitations of this form of research by maintaining 95% retention over 18 months, indicating that participants managed the email format and retained their interest in the subject. The mixed design study15 obtained their data using quantitative survey of hospital staff and interviews of family members to assess the need for a palliative care programme. This study did not report the reasons for the mixed design; however, the limitations regarding reliability and validity were acknowledged and the themes were offered as suggestions only. These themes, however, were similar to those produced by other studies.

Despite the limitations of the studies reviewed, the findings provide a stimulus for further research in the area of neonatal palliative care, in particular, looking at the experience of the nursing staff. Kain16 relates that nursing research into the care of critically ill newborns needs to be broad-ranging and “conversant across the multiple paradigms and perspectives that inform this research field”. Kain states that the social discourse of these perspectives makes an important contribution to the development of this burgeoning knowledge. The potential of these studies to add to the debate surrounding neonatal palliative care and to contribute to or stimulate further research into the area is of great benefit despite the limitations mentioned.

Results

A thematic framework was used to analyse the literature and the guidelines used were provided by Taylor et al.10. Four themes emerged that were relevant to the majority of articles and depicted the nurses’ experience of and difficulties with providing palliative care to the neonatal and paediatric populations. These themes included palliative versus curative care, feelings of ambiguity or ambivalence towards the use of technology in care, the role of experience and education in nurses’ ability to manage palliative care and the factors influencing nurses’ emotional wellbeing and practice.

Palliative versus curative care

Nurses frequently reported feeling distressed when trying to manage the transition from curative to palliative care and this emerged as a theme from seven of the studies13,14,17-21. This occurred most prominently in the studies relating to children with cancer and oncology, but was also apparent in a different way with the infants. In these instances, while the prognosis was rather clearer, that is despite medical intervention the infant would die, the uncertainty arose in relation to when life support should be turned off or when invasive procedures should be stopped. This is a theme in its own right to be discussed later.

The paediatric literature, in particular Davies et al.18, explores the notion that an uncertain prognosis for children with life-limiting illness makes it difficult to predict accurately the treatment responses or the overall chances for the child’s survival. The importance of this issue in neonatal care becomes apparent as Davies et al.18 report that the resulting uncertainty encourages parents and, thus, medical staff, to pursue curative treatment until they are sure of the outcome. This means that palliative care is instituted late in the child’s course of treatment, thus delaying the psychosocial support and care a palliative approach could offer. This occurs similarly...
in neonatal care as those involved in an infant’s care pursue treatment at the cost of recognising the reality of an infant’s poor outcome. This was drawn out in the study by Catlin et al., where nurses described becoming uncomfortable when physicians were focused on “saving life” and “furthering the advancement of science”. The nurses wanted to object when parents would not agree to a change to palliative care. Catlin et al. described this as “conscientious objection”. They noted that many of the nurses had wanted to object to interventions that they perceived as not conducive to prolonging life. Additionally many of these nurses had wanted to voice their objections and voice their support for palliative care; however, when faced with the doctor’s orders for care and the families’ wish to continue in a curative vein, the nurses put their personal beliefs aside and followed through with the care orders. Yam et al. reported on the nurses’ sense of ambivalence when asked to perform procedures on the doctor’s orders when they believed less invasive procedures seemed more appropriate. Nurses in this study spoke of not knowing how to manage the infant’s care when they were expected to provide both curative and palliative care.

In the study by Kaempf et al., women at risk of premature birth were offered pre-viability counselling. The data from the women with whom follow-up occurred revealed that when families receive counselling and medical information regarding the viability of their infant, a substantial number will decline intensive care. They then choose a palliative care pathway for their infant, provided by staff with respect and mutual understanding. The authors acknowledged that parents are the ultimate decision makers for their infants but believed that the collaborative decision-making process which recognised cultural sensitivities and included the rational analysis of the infant’s medical status enabled informed choices without resorting to medical experts and neonatal intensive care as the most expedient option.

De Graves and Aranda found that the uncertainty surrounding the possibility of cure from the pursuit of curative efforts and the ever-present element of hope, leaves the professionals involved questioning how palliative care can be implemented when active treatment still persists and the family are not ready to accept palliative care as an option. These decisions were identified as the most difficult and challenging for both families and the staff and possibly reflects a disconnect regarding the goals of treatment. It was suggested that there is a need for models of palliative care that can be implemented throughout the time of care as a child (in this instance) approaches death, that do not forgo the need for life-prolonging treatments.

Ambiguity/ambivalence towards the use of technology

Nurses are at the forefront of providing care for their patients, implementing treatments and providing medications. This occurs despite often unspoken disquiet on behalf of the nurse regarding the futile nature of such treatments. Five of the studies reviewed explored the notion of ambivalence towards the invasive use of technology. One study noted that “... the actual impact of technological imperatives and whether this results in ethical and moral concerns for the neonatal nurse have not been studied before”.

Nurses described the dilemmas they experienced while working with infants on the very threshold of life. Many nurses were able to express their concerns, as in the study from Hong Kong where nurses reported that in response to situations where the infant was dying, they were most concerned with enhancing the quality of life during the period of dying. In doing this, the nurses were working towards establishing consensus with other members of the team regarding the discontinuation of treatment.

In a study of Australian nurses, it was reported that over 62% of neonatal nurses had participated in technological care that went beyond what they felt comfortable with and 75% of these nurses said they had been asked by parents to continue life-extending care beyond what they felt was appropriate. Kain et al. reported that these figures support literature that has reported on the perception of nurses that they have harmed infants or contributed to their suffering when they could have provided comfort care. Additionally, Kain et al. identified that the struggle between the competing demands of technological imperatives and parental demands may lead to moral distress for the nurses involved.

Conversely, in the report by Lee and Dupree, it was found that staff acknowledged the benefits technology had provided in sustaining life. This was countered, however, when staff recognised the invasiveness of treatment and they highlighted their own dilemmas when describing occasions when a child’s life was sustained beyond what was desired or to the point of the “person” no longer being there.

In the study on conscientious objection, Catlin et al. asked nurses to add further thoughts regarding this concept. Nurses stated that they wanted guidance from professional nursing organisations regarding their role and responsibilities at times when they want to object to therapies that would not change the underlying condition of their patients. The nurses participating in this study expressed interest in the concept of conscientious objection as a means of enabling them to work within their own moral frameworks. While palliation has become an accepted form of care in the paediatric sphere, for infants the barriers to implementing a palliative care plan include a lack of training and support for the nurses involved and a lack of agreement about the goals of care among members of health care teams.

The role of experience and education in managing palliative care

Four of the studies revealed that nurses with education and experience in providing palliative care were better able to manage the complexities of this form of care.

The study by Feudtner et al. of paediatric nurses revealed that nurses reporting greater levels of comfort in working with dying children and their families and with a greater depth of competency in providing palliative care had more years of experience.
of experience and palliative care-specific education. When oncology nurses were asked which attributes they thought were required for palliative care one of the most important was being knowledgeable28. This included the nurses’ clinical expertise regarding the disease and treatment, but also centred on knowledge regarding alleviating symptoms and improving quality of life. Through using their knowledge, the nurses believed they were able offer patients individualised care and thus improve the quality of life outcomes for patients, even while they were dying.

In contrast, however, the study outlined by Engler et al.26 found that although nursing staff had received education in bereavement and end-of-life care, less than half found this to be helpful. Although it was noted that nurses with experience and education were more comfortable working with dying infants and bereaved families, Dickens25 researched the factors that create competence with end-of-life issues. This study revealed that despite recent increases in education regarding paediatric palliative care, there was not a corresponding increase in education that would address many of the issues surrounding palliative care in the paediatric population. Dickens25 suggested that the age of the care provider/nurse was perhaps a more important variable associated with confidence in end-of-life care. In turn, the sense that palliative care was successful in the reports cited above indicates that palliative care was implemented early on in the infant’s care plan by staff, particularly the nurses, who were competent and comfortable initiating and implementing this process at an appropriate time.

Factors influencing the nurses’ emotional wellbeing and practice

The emotional wellbeing of the staff providing palliative care is a critical element to providing comprehensive care for neonates and their families. As stated earlier, the nurses’ role of one-on-one care for the infant places them in the unique position where they have contact with everyone involved in the care of that infant, from family to medical staff. The emotional burdens placed on nurses are, therefore, significant. Throughout all of the studies reviewed, the underlying theme was a concern for the nurses and their personal wellbeing. Nurses’ feelings of stress and distress experienced while working with infants and their families during the time leading to an infant’s death and managing the parents’ and families’ grief once this has occurred need to be acknowledged and managed well to avoid burnout and departure from the profession. Lee and Dupree24 found that staff in a paediatric setting overwhelmingly reported feeling sad. This related not only to death of the child but also because they were a part of the family’s grief. Interestingly, staff in this study believed their response was positive as it indicated that they were still in touch with what they were doing and remained emotionally available to their patients.

When families and nurses were asked to define the important attributes of palliative care nurses, one of the most significant was their personal traits29. The nurse was expected to be professional and friendly, with an ability to provide reassurance and security while remaining accessible and “real” to the patients. Further to understanding the nurses’ sense of wellbeing with their practice, Pavlish and Ceronsky28 found that collaboration was an attribute the nurses felt was essential to their role in the oncology setting. This has implications for the neonatal palliative care setting as collaboration was described as “the spirit within which nurses entered the nurse–patient relationship”29. The nurses reported expending considerable time coordinating services and being “diplomatic” as they managed the patient, family and team when a terminal diagnosis was made.

Of concern throughout the studies were the reports by nursing staff that they were not supported by the institutions they worked for, especially following a patient’s death. Contro et al.13 found that staff in their study felt unable to grieve following the death of a child. They would return to work immediately, with no place to discuss what had happened and with painful memories. These feelings of isolation extended to the families involved in the death as no formal structures were in place for ongoing emotional support.

Discussion

Neonatal palliative care is a complex field of nursing, yet can be highly rewarding. Nurses who choose to work in this area experience the highs and lows of their profession in ways that many others may not. The birth of an infant is a time of rejoicing, but when that infant dies despite the efforts of all involved, the parents’ overwhelming grief and a sense of failure on behalf of the hospital staff may be the result.

Paediatric palliative care and the research in associated fields such as oncology have proven to be invaluable in aiding a greater understanding of the issues that may arise for the neonatal population in regard to palliative care. As Shotton30 states, end-of-life care presents nurses with particularly difficult ethical dilemmas because of the many uncertainties that it involves. Moro et al.31 acknowledge that these decisions are traumatic for both parents and health care providers. However, once death becomes inevitable for the infant, “the goal of care is to assure that the infant dies with dignity, free from pain or distress”31. When and how this occurs becomes mired in the decisions surrounding the move from curative to palliative care and ending the potentially inappropriate technological treatments being administered. Nurses expressed concerns throughout the research that they were treating infants beyond what was, in their professional opinion, appropriate, and were caught between the competing needs of the infant, their parents and the medical team supporting the infant’s care.

Neonatal palliative care protocols have begun to be implemented in many neonatal intensive care units (NICUs), but despite the number of deaths in the units, the use of palliative care and the associated principles remains low. Palliative care principles when employed as a part of a care plan can provide nursing staff with focus and a sense of making a valuable contribution to the end-of-life care of their patient, the infant. Carter4 emphasises that decisions made regarding the ongoing care of the infant, whether
life-prolonging or palliative, need to be framed around the individual infant's wellbeing and the goal for staff should be collaborative decision making. This is crucial when the infant's death is predicted and decisions are being made to remove or withhold non-beneficial interventions that would only prolong the infant's suffering and impede the transition to palliative care.

A palliative care protocol devised by a multidisciplinary team may help bring consensus to the use of such a protocol when planning care in the NICU. While the parents remain the ultimate decision makers regarding the withdrawal of care for their infant, a protocol enables each member of the infant's team a structured means of contributing to the decisions being made. Throughout the studies the often unspoken nature of the nurses' responses reflected a belief that their concerns regarding seemingly inappropriate treatments were not able to be voiced, thus undermining the nursing role in the infant's care plan. This can impact upon the nurses' sense of emotional wellbeing and sense that they are valued for the skilled role they perform in the infant's care.

Future research should focus on the nursing experience of providing palliative care with the very young. Caring for these infants, the most vulnerable members of our community, requires outstanding commitment, both personally and professionally, on behalf of everyone, but notably the nurses. It is important that nurse's skills, knowledge and compassion are recognised and that their concerns are listened to and respected. Research into neonatal palliative care, ways of improving the implementation of protocols, along with studies into the nurses' experience of providing neonatal care is vital to ensuring that the nursing profession respects and supports its members as they carry out this invaluable work.

Nurses also need to be committed to improving care through a willingness to embrace new information and protocols that seek to improve the end of life for their patients. Shotton reflects on competent and ethical care, stating that this is only possible when nurses are committed to maintaining their knowledge and skills at a level that benefits rather than harms their patients.

Conclusion

This review has shown the importance of establishing a comprehensive understanding of the role of the nurse in neonatal palliative care, the barriers faced by the nurses and strategies that could be implemented to improve the implementation of protocols for palliative care. Future research in this area will inform and enhance current nursing practice. Nurses working with infants, their families and the multidisciplinary team involved in the care provided by an NICU, develop experience, understanding, empathy and compassion for their work that has the potential to be lost to the profession if their experiences are not sought out and validated. This review of the literature seeks to highlight the complex nature of the work undertaken by neonatal nurses and to provide impetus for future research to further inform and benefit neonatal care and the nursing profession.

If we are able to improve quality at the end of life for patients and families, it is our obligation to do it. After all, their hopes and dreams for the future die with their infant, their memories should include the knowledge that their baby was comfortable and well cared for until the end. (Elizabeth Maginnes, MD (2002)).

References

<table>
<thead>
<tr>
<th>Study</th>
<th>Author, year, country</th>
<th>Aim</th>
<th>Sample</th>
<th>Methodology</th>
<th>Major findings</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Burns, Mitchell, Griffith, Truog, (2001) USA</td>
<td>To determine attitudes and practices of paediatric critical care attending physicians and paediatric critical care nurses on end-of-life care</td>
<td>A random sample of clinicians at 31 paediatric hospitals. Of the 130 questionnaires sent, 110 physicians and 92 nurses completed and returned the survey.</td>
<td>Qualitative, self-administered questionnaire.</td>
<td>None agreed with statement that “withholding or withdrawing life support is unethical”. Increase analgesia and sedation... discontinued. Association between fewer years of experience and reluctance to withdraw life-sustaining treatment.</td>
<td>No information on non-respondents. Low response rate.</td>
</tr>
<tr>
<td>2</td>
<td>Catlin, Carter (2002) USA</td>
<td>To create a protocol delineating the needs of patients, families and staff necessary to provide a pain-free, dignified, family- and staff-supported death for newborns who cannot benefit from intensive, life-extending, technological support.</td>
<td>101 participants over 18 months, from 93 locations in the US, 4 international participants gave feedback to 13 questions derived from clinical experience and literature. Participants were doctors, nurses, other professions.</td>
<td>Using internet email, a Delphi study with sequential questionnaires soliciting participant response.</td>
<td>Palliative care team approach. Staff to be familiar with, ready to implement palliative care, support, and symptom management. Which newborns should receive palliative care, how to approach parents? Optimal environment for neonatal death. Specific skills needed by staff to provide palliative care. Ongoing staff support.</td>
<td>Dependent upon participants ability to manage email, internet format. Length of study – over 18 months.</td>
</tr>
<tr>
<td>3</td>
<td>Catlin, Volat, Hadley, Bassir, Armigo, Valle, Gong, Anderson (2008) USA</td>
<td>An exploratory effort regarding conscientious objection. This was proposed as a potential response to the moral distress experienced by neonatal nurses when following orders to support patients at the end of their lives with advanced technology when palliative or comfort care would be more humane.</td>
<td>Data from 66 NICU and PICU nurses who responded over a 1-month period.</td>
<td>Qualitative questions posted on the University website. Four demographic questions, 11 multiple choice and open-ended questions.</td>
<td>Most respondents wanted to object to aggressive and technologic interventions for newborns at 22–24 weeks' gestation, or who are born with conditions incompatible with life. Curative vs palliative care. Many had acted or wanted to voice their objections to care orders. What support would they receive if they voiced these concerns?</td>
<td>Pilot study.</td>
</tr>
<tr>
<td>4</td>
<td>Contro, Larson, Scofield, Sourkes, Cohen (2004) USA</td>
<td>The development of a paediatric palliative care programme was preceded by a needs assessment that included a staff survey and family interviews regarding improving paediatric palliative care.</td>
<td>446 staff from one children’s hospital, 191 were nurses from a range of specialities. 68 family members of deceased children.</td>
<td>Quantitative and qualitative survey.</td>
<td>Inexperience in communication with families from physicians. Pain and symptom management a concern. Inadequate support for staff providing end-of-life care. Debriefing needed. Most respondents would welcome consult with a palliative care team.</td>
<td>Sampling errors and self-selection bias. Single practice setting.</td>
</tr>
<tr>
<td>Volume 16 Number 1 – March 2013</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---------------------------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>NEONATAL, PAEDIATRIC AND CHILD HEALTH NURSING</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td>Dickens (2009) USA</td>
<td>To collect data on health care providers who provide paediatric end-of-life care to determine what factors influence provider confidence in managing end-of-life care for children.</td>
<td>Quantitative, cross-sectional, descriptive, mailed survey design.</td>
<td>15% response rate.</td>
<td>Single practice setting.</td>
</tr>
<tr>
<td>8</td>
<td>Engler, Cusson, Brockett, Cannon-Heinrich, Goldberg, West, Petow (2004) USA</td>
<td>To describe neonatal nurses’ perceptions of bereavement/end-of-life care for families of critically ill and/or dying infants.</td>
<td>Quantitative, web-based, cross-sectional questionnaire.</td>
<td>52% response rate.</td>
<td>Single practice setting.</td>
</tr>
<tr>
<td>9</td>
<td>Feudtner, Santucci, Feinstein, Snyder, Rourke, Kang, (2007) USA</td>
<td>To test the hypothesis that individual nurses’ level of hope is associated with greater self-reported comfort in providing palliative care.</td>
<td>Quantitative, web-based, cross-sectional questionnaire.</td>
<td>44% response rate.</td>
<td>Single practice setting.</td>
</tr>
<tr>
<td>10</td>
<td>Hale, Long, Sanderson, Carr (2008) UK</td>
<td>Third stage of a research study to evaluate the educational needs and preparation of nurses in caring for children receiving palliative care.</td>
<td>Video and audio recordings of practice with explanatory commentary from nurses and family, qualitative interviews.</td>
<td>75% response rate.</td>
<td>Single practice setting.</td>
</tr>
<tr>
<td>11</td>
<td>Kaempf, Tomlinson, Campbell, Ferguson, Stewart (2009) USA</td>
<td>To describe implementation of medical guidelines used for counselling pregnant women threatening to give birth between 22 and 26 weeks’ gestation.</td>
<td>Qualitative interviews.</td>
<td>75% response rate.</td>
<td>Single practice setting.</td>
</tr>
<tr>
<td>#</td>
<td>Authors</td>
<td>Study Title</td>
<td>Methods</td>
<td>Findings</td>
<td>Limitations</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>12</td>
<td>Kain, Gardner, Yates (2009) Australia</td>
<td>To obtain an understanding of barriers to and facilitators of providing palliative care in neonatal nursing. First phase of research.</td>
<td>1285 neonatal nurses in Level 3 NICUs within Australia, 1285 neonatal nurses, 645 returned, response rate of 50%. quantitative, questionnaire included eight demographic questions and 26 attitude questions.</td>
<td>Support for neonatal palliative model of care. A team that can express values, opinions, beliefs is valuable. Need clinical guidelines to support practice. Inadequate staffing. Physical environment not conducive to palliative care. Technological imperatives and parental demands.</td>
<td>Further testing of the reliability of the instrument used was required.</td>
</tr>
<tr>
<td>13</td>
<td>Lee, Dupree (2008) United States</td>
<td>Describe experiences of (PICU) staff caring for a child who dies, to determine whether responses included unprompted indications of moral distress as described in the literature.</td>
<td>29 staff including nurses, physicians, and psychosocial support, relating to 8 patient deaths. Qualitative, descriptive study, semi-structured interviews.</td>
<td>Importance of communication for effective decision-making. Ambiguity about use of technology. Feelings of sadness. Limited emotional support following a death.</td>
<td>Single practice setting.</td>
</tr>
<tr>
<td>14</td>
<td>Pavlish, Ceronsky (2009) USA</td>
<td>To explore oncology nurses' perspectives of palliative care through narrative analysis of participants' descriptions of life experiences (not a paediatric setting).</td>
<td>33 oncology nurses from 3 medical centres. Qualitative. Nine focus groups, discussion using a semi-structured interview guide.</td>
<td>Palliative care encompasses working with patients, families, to alleviate suffering, achieve holistic comfort and wellbeing, and attain patients' quality of life goals. Five nursing roles: teaching, caring, coordinating, advocating, mobilising. Seven professional attributes: honesty, family orientation, perceptive attentiveness, presence, collaboration, deliberateness.</td>
<td>None mentioned.</td>
</tr>
<tr>
<td>15</td>
<td>Samaan, Cuttini, Casotto, Ryan (2008) Ireland</td>
<td>To explore staff attitudes towards ethical decision making in NICUs in Ireland, to establish differences between doctors and nurses, to compare attitudes in Ireland with those in Europe.</td>
<td>64 doctors and 228 nurses in 7 NICUs. 74% and 81% response rates respectively. Quantitative, cross-sectional study by use of an anonymous questionnaire.</td>
<td>Setting limits to intensive interventions may be ethically justified, when in accordance with best interests of patient. Clinicians found it easier to withhold rather than withdraw intensive care.</td>
<td>None mentioned.</td>
</tr>
<tr>
<td>16</td>
<td>Yam, Rosier, Cheung (2001) Hong Kong</td>
<td>Explore experiences of neonatal nurses in Hong Kong caring for dying infants, their perceptions of palliative care, and factors influencing their care. The infants were less than 12 months old, not responsive to curative management, and were expected to die in the NICU.</td>
<td>10 registered nurses from NICU/SCBU, 1 hospital, all female. Convenience sampling, qualitative, semi-structured, open-ended questions, individual interviews.</td>
<td>Palliative vs curative care. Enhancing quality of life during period of dying, rather than aggressive curative management. Consistent approach in ceasing invasive care, reducing infant's pain and suffering. Lack of policy direction, support for provision of palliative care in unit, focus curative management.</td>
<td>Small sample size and single practice setting. Difficulty in achieving accurate translation of the verbatim data from Cantonese to English.</td>
</tr>
</tbody>
</table>
The Australian College of Neonatal Nurses Inc. (ACNN) is delighted to host the 8th Annual Conference in Townsville, Queensland, Australia.

*The ACNN Conference Day and Symposium* will provide a forum for health professionals to explore the challenges we face in providing optimal care for our small clients, their families and their communities.

We invite you to attend this exciting conference and seminar to reflect on practice and to share innovative ideas and experiences with colleagues.

**For further information contact:** Karen New / Ph: 0432 006 567 / Email: theprofessionalofficer@acnn.org.au  
Visit our website for up to date information:

www.acnn.org.au
Prevalence of assigned primary nurses in a neonatal intensive care unit during the period 1998–2007

Johannes van den Berg*
Department of Clinical Sciences, Pediatrics, Umeå University, SE-901 85 Umeå, Sweden
johannes.berg@pediatri.umu.se

Viveca Lindh
Department of Nursing, Umeå University, SE-901 85 Umeå, Sweden

Abstract
The implementation of primary nursing is expected to improve nurse–patient relationships and increase individuality in nursing care. However, it is apparent that not all families have had "primary nurses" during hospital stays. To what extent primary nurses have been assigned to neonatal intensive care unit (NICU) families has not been described. The aim of this study is to report the prevalence of primary nursing care and elucidate whether the assignment of primary nurses increases the prevalence of admission interviews and written discharge summaries in an NICU setting in Sweden.

Methods From 1998 to 2007, a total of 3,397 infants were admitted to a single NICU, of which 3,094 were included in this study. The following variables were collected: infant birth weight (BW) and gestational age at birth (GA), whether the family was assigned a primary nurse, whether the primary nurse performed an admission interview, and whether a discharge note was written.

Results Primary nurses were assigned to 50% of families, according to the 3,094 charts examined. An admission interview with the primary nurse was documented in 41% of cases, and a written discharge note was recorded in 36%. Families with infants born ≤32 weeks GA were assigned primary nurses significantly more often than families whose infants were born ≥33 weeks GA. There were significant correlations between the prevalence of primary nurse assignments, admission interviews with families and the writing of discharge notes.

Conclusion Assigning primary nurses to families increases the likelihood of both admission interviews being conducted at the start of NICU stays and discharge notes being written at the end of NICU stays, making visible that nursing care plans have been implemented and that follow-up plans have been forwarded to primary health care providers. More effort should be made to increase the prevalence of assigned primary nurses and to further study whether this is a determinant of nursing care quality.

Keywords Primary nursing, support, relationship-based, neonatal intensive care, infants.

What is known about this topic
• Primary nursing, often called relationship-based care, is an important part of family-centred neonatal care.
• Primary nursing has been shown to be associated with reduced job satisfaction, stress and uncertainty about how the primary nursing model should be organised.

What this paper adds
• In an NICU in Sweden, where primary nursing is a model of care, primary nurses were assigned to only half of infants and families; admission interviews were documented in 41% of cases, and a written discharge note was recorded in 36%.
• Families with infants born ≤32 weeks GA were assigned primary nurses significantly more often than families whose infants were born ≥33 weeks GA.

Declarations
This manuscript has been prepared according to the instructions provided at www.cambridgemedi.com and has not been submitted elsewhere. The certification of authorship and copyright form have been sent in accordance with the instructions.

Competing interests Nil.
Funding Nil.

Ethical approval Not submitted to the regional ethical review board, as it was not a clinical trial.

Guarantor JB.

Contributorship Study conception, design, data analysis, drafting of manuscript, critical revisions – JB, VL; data collection and statistical expertise – JB.

Acknowledgements Nil.
Introduction
Throughout the late 1980s and early 1990s, improvements in perinatal care, including new ventilator techniques, surfactant therapy, and maternal pre-delivery steroids, increased the survival of very low birth-weight infants. Nursing care in neonatal intensive care units (NICUs) in Sweden faced challenging technical demands during this period, and nursing became largely task-oriented and focused on technical skills. However, the influence of more patient- and family-centered models for nursing care, in general, and for neonatal nursing care for preterm infants, in particular, was seen as early as the mid-1980s.

The primary nursing model is seen as a means of moving towards patient-oriented systems for nursing. A single professional nurse is given the authority to take 24-hour responsibility for the coordinated, continuous and individual care of a particular patient's family. Primary nursing has also been described as a philosophy of care. There is lack of consensus on the definition of primary nursing, and it is arguable whether primary nursing is a model of care or a philosophy of nursing. However, the originator of "primary nursing" defines it as a nursing practice that emphasises continuity of care by having one nurse provide complete care for a small group of inpatients or families within a nursing unit of a hospital. The "primary nurse" is responsible for coordinating all aspects of care for the same patients/families throughout their stay, for example, in the hospital. The primary nurse's responsibility begins the first day, with patient-care planning, including an admission interview and a care plan documented in the nursing record, and ends with a discharge note, also kept in the record, and contact with the well-baby clinic or the hospital to which the baby is transferred.

The primary nursing model also fits well with the relationship-based philosophy of the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) and family-centred care (FCC) introduced in neonatal nursing in Sweden during the 1990s.

An important issue in primary nursing is the benefit of the primary nursing model. Although it has been suggested that primary nursing improves the standard of care for infants and their families, there have been some concerns about the heavy responsibility borne by individual nurses for "difficult" patients with long hospital stays. Support and good communication within multidisciplinary care teams, the presence of named nurse assistants, and the opportunity to take breaks from patients have all been mentioned as means of facilitating primary nursing. However, changes in the system can provoke a variety of reactions. When primary nursing was implemented in a neonatal unit in Canada, parents were satisfied with the model of care, but nurses' job satisfaction decreased, which suggests the need for some facilitating measures. Moreover, there seems to be a lack of evidence in the existing literature as to whether primary nursing improves patient outcomes. There are some reports that suggest other research approaches with more exactly defined tasks may show effectiveness of the primary nursing model. However, these reviews are dated, and more recent reviews have not indicated the same. Other reports suggest that team-nursing is more effective than the primary nursing model, especially when it comes to job satisfaction. In reality, many nurses feel insecure about taking on new responsibilities and have hesitated to adopt the primary nurse role. The process of selecting patients and assigning some, but not others, a primary nurse may depend on several medical and staff factors. This suggests the possibility that not all infants will be assigned primary nurses, and, therefore, it may be questioned whether the primary model in individual NICUs and among several departments is really fully implemented.

Although primary nursing was officially implemented in this Swedish NICU with the goal of providing good-quality nursing care, it is apparent that some families were not assigned primary nurses during their hospital stays. To our knowledge, no previous studies have focused specifically on the actual prevalence of primary nursing assignments to families in NICUs that support the primary nursing model of care.

The aim of this study is to report the prevalence of primary nursing care and elucidate whether the assignment of "primary nurses" increases the prevalence of admission interviews and written discharge summaries in an NICU setting in Sweden.

Methods
Population, reception area and the northern Swedish region of health and medical care
Sweden is divided into six regions of health and medical care, each including at least one university hospital with a level III NICU. The northern health and medical care region in Sweden is the largest and consists of four county councils in a sub-arctic area of 225,464 square kilometres, comparable to the UK, excluding Northern Ireland, and with a population of approximately one million inhabitants. This corresponds to about half the area of Sweden and less than 10% of the total Swedish population. The northern region's level III NICU, at the University Hospital of Northern Sweden in Umeå, serves seven referring community hospitals with paediatric/neonatal wards. The average annual number of live births in the northern region during the period 1998 to 2007 was 8,466 (SD 365), of which, on average, 340 (SD 23) were admitted to the NICU in Umeå.

Setting, staffing and philosophy of care
During the period covered by this study, the NICU at the University Hospital of Northern Sweden was comprised of eight intensive care beds and 12 intermediate care beds, divided into three four-bed rooms and four single/double rooms. The staff consisted of about 60 nurses and assistant nurses, five neonatologists, and 10 administrative and support personnel. The staffing of nurses and assistant nurses was divided into three shifts per 24 hours. The NICU had a written philosophy of FCC, which encourages partnership
between staff and families and includes a NIDCAP-inspired developmental care programme for infants.6,21,22.

The primary nurse is principally responsible for the nursing care provided to the infant and the family, for identifying the family’s needs, for implementing the nursing care plan and for coordinating care during the NICU stay. However, since the nurse cannot provide care 24 hours a day, and since staffing issues may demand that she be involved elsewhere, the primary nursing responsibilities can be shared by another nurse or an assistant nurse, to ensure the continuity of care. The memorandum sheet (see below) helps other nurses or the assistant primary nurse carry out some of the primary nursing responsibilities. These are: to ensure that every family is offered a sit-down admission interview, given a picture of the newborn infant, given written information on ward routines (collection of standard blood samples, hygiene routines and so on), and given a guided tour of the ward. To prepare the family and the staff at their referring community hospital (CH) and welfare centre for further care after discharge from the NICU, both the CH and the welfare centre are notified that the infant has been born and that the family has been admitted to the ward. When the family is ready for discharge or transportation to the CH, a discharge note is written by the primary nurse.

A nurse is commonly considered eligible to be a primary nurse after working in an NICU unit for at least six months. To be considered eligible to be a primary nurse for families whose infants are in need of neonatal intensive care, a nurse must have had further education in neonatal intensive care and completed a period under supervision by a senior nurse.

The kardex

When an infant is admitted to an NICU, a medical chart is created. This chart includes a memorandum sheet, called the “kardex”; on which staff make notes during the infant’s and family’s hospital stays. The kardex consists of 19 boxes, representing five different areas of care: administrative, medical, nursing, communications and tasks. Each box comprises one or more of a total of 78 variables. For the purpose of this study, we examined the following outcome variables: prevalence of assigned primary nurses, admission interviews, and discharge notes. Gestational age at birth (GA) and birth weight (BW) were recorded, to evaluate their relationships with the dependent variables.

Data collection

After an infant is discharged from an NICU and returned home, back-transported to CH, or referred to another hospital for further specialised care, selected variables from the kardex are entered into a data file. During the period 1998 to 2007, a total of 3,397 infants were admitted to the NICU in this study, for whom 3,094 kardexes (91%) were available. The remaining 303 kardex were not found or were insufficient/incomplete. The outcome variables (primary nurse, admission interview, and discharge note) were coded as either “yes” or “no”, that is, “yes” when a primary nurse had been assigned to the family and “no” when one had not. For comparison, the infants were grouped by GA into GA<28, GA=28–32, GA=33–36, GA=37–43, and admitted from home (infants admitted to the NICU from home and not from the delivery ward or other hospital).

Statistical analysis

SPSS software (SPSS, Chicago, Ill.) was used for statistical analysis. The data were summarised using descriptive statistics. Spearman’s rank correlation was used to measure correlations between variables. Non-parametric statistics, the Kruskal Willis test, and the Mann-Whitney U-test were used to compare groups of non-parametric data. Statistical level of significance was set to $p<0.05$ for the primary test (Kruskal Willis) and to $p<0.01$ for multiple post-hoc tests (Mann-Whitney U-test).

Results

Overall

Over the 10-year period, the assignment of primary nurses to infants and families was recorded in 50% ($n=1559$) of the 3,094 kardexes examined (min 24%, 3rd quarter 2006; max 80%, 1st quarter 2004). Admission interviews were documented in 41% ($n=1270$) of the kardexes (min 23%, 1st quarter 2000; max 73% 4th quarter 2004), and a discharge note was recorded in 36% ($n=1109$) of kardexes (min 8%, 3rd quarter 1999; max 55%, 4th quarter 2003) (Figure 1). Infant BW was documented in 90.9% ($n=2804$) of kardexes, and the mean BW was 2,721 grams (SD 1.121 g). Infant GA was documented in 99.9% ($n=3092$) of kardexes, and the mean GA was 35 weeks (SD 5 wks).

Relationship between primary nurses, admission interviews, discharge notes and infant GA

There were significant correlations ($r=0.815; p<0.01$) between the assignment of a primary nurse and whether a family received an admission interview and a written discharge note ($r=0.336; p<0.05$). The correlations are graphically presented in Figure 2.

When analysed by infant GA, the prevalence of primary nurses, admission interviews and written discharge notes was highest in the group of premature infants born before 28 weeks’ gestation (GA<28). The frequencies of these variables decreased gradually for infants in groups with higher GA and infants admitted from home (Figure 3). This difference between GA groups was significant ($p<0.001$, Kruskal Wallis). Post-hoc tests (Mann Whitney U-test) of differences between specific GA groups showed no significant difference between the group GA<28 and the group GA=28–32 for the three outcome variables of primary nurse, admission interview, and discharge note. However, both these groups, GA<28 and GA=28–32, differed significantly from all other groups. Further, significant differences were also found between the groups GA=33–36, GA=37–43, and admitted from home for all variables except the prevalence of an assigned primary nurse for the group GA=37–43, compared with the group admitted from home (Table 1).
Discussion

The aim of this study was to describe the prevalence of primary nurses assigned to NICU families during the 10-year period from 1998 to 2007 in a level III NICU in Northern Sweden. The key question asked was: what tasks associated with the primary nurse role were fulfilled, and how were primary nurses distributed among infants born at different gestational ages? The main findings were that 50% of families were assigned primary nurses; 41% had admission interviews with their primary nurses, and in 36% of cases, nursing care discharge notes were written. Infants born at an early gestational age (≤32 weeks GA) were assigned primary

![Primary nurse prevalence chart](image)

Figure 1. The quarterly prevalence (%) of assigned primary nurses, admission interviews and written discharge notes for the period 1998–2007.

Table 1. Post-hoc comparisons of the prevalence of primary nurses, admission interviews and discharge notes between infants grouped by GA and those admitted from home. The left column shows the three variables and their prevalence (%) in each GA group (second column from the left). The upper part of the table (above the grey shaded boxes) shows the p-value, while the lower part shows the Z-score. Significance level was set to p<0.01.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Infants grouped by GA</th>
<th>GA &lt;28 (n = 293)</th>
<th>GA = 28 - 32 (n = 391)</th>
<th>GA = 33 - 36 (n = 709)</th>
<th>GA = 37 - 43 (n = 1488)</th>
<th>Admitted from home (n = 211)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary nurse</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>90%</td>
<td>GA &lt;28</td>
<td></td>
<td>0.134</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>89%</td>
<td>GA = 28 - 32</td>
<td>-1.498</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>59%</td>
<td>GA = 33 - 36</td>
<td>-7.453</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>33%</td>
<td>GA = 37 - 43</td>
<td>-15.498</td>
<td>-7.543</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>0.137</td>
</tr>
<tr>
<td>19%</td>
<td>Admitted from home</td>
<td>-9.05</td>
<td>-8.197</td>
<td>-4.793</td>
<td>-1.486</td>
<td></td>
</tr>
<tr>
<td>Admission interview</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>81%</td>
<td>GA &lt;28</td>
<td></td>
<td>0.029</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>73%</td>
<td>GA = 28 - 32</td>
<td>-2.178</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>50%</td>
<td>GA = 33 - 36</td>
<td>-9.069</td>
<td>-7.682</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>25%</td>
<td>GA = 37 - 43</td>
<td>-18.294</td>
<td>-11.391</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>11%</td>
<td>Admitted from home</td>
<td>-15.418</td>
<td>-14.628</td>
<td>-10.017</td>
<td>-4.554</td>
<td></td>
</tr>
<tr>
<td>Discharge note</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>58%</td>
<td>GA &lt;28</td>
<td></td>
<td>0.102</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>52%</td>
<td>GA = 28 - 32</td>
<td>-1.635</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>40%</td>
<td>GA = 33 - 36</td>
<td>-5.244</td>
<td>-3.789</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>28%</td>
<td>GA = 37 - 43</td>
<td>-10.112</td>
<td>-5.757</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>0.002</td>
</tr>
<tr>
<td>18%</td>
<td>Admitted from home</td>
<td>-9.141</td>
<td>-8.214</td>
<td>-6.022</td>
<td>-3.166</td>
<td></td>
</tr>
</tbody>
</table>
nurses significantly more often than were infants born after 32 weeks GA. The prevalence of primary nurses correlated positively and significantly with admission interviews and written discharge notes.

The overall low rate of assigned primary nurses and written admission interviews and discharge notes might be seen as the result of a strained nursing workload during this period, with nurse-to-patient ratios touching the limit for safe medical care. Care turned out to be fragmented when medical acuity of the baby mainly governed the NICU staffing. Other primary nurse responsibilities, such as continuity of nursing care and communication with families throughout hospital stay, to promote health and facilitate coping support, might not have been equally considered when staffing the NICU. When nursing resources are limited, the activities most frequently rationed by neonatal nurses are discharge planning, parental support and comfort care. Hamilton et al. have shown that the proportion of well-trained neonatal nurses per shift correlates with the survival of very low birth-weight infants.

In this NICU, the percentage of nurses with specialist nursing degrees was low during the study period, which might have had an impact on assignment of primary nurses and nursing care quality.

NICU nurses’ work stress has been escalating, due to increasing use of technology and advanced intensive care since the mid-1980s. The landmark document To err is human, published by the Institute of Medicine (IOM), has recently changed ways of thinking about patient safety in intensive care, making it more a product of team performance and communication skills, rather than solely the result of individuals’ medical and technical skills. Standards for establishing and sustaining healthy work environments for critical care nurses point out the need for appropriate leadership and staffing and suggest that nurses must be as proficient in communication as they are in clinical work.

In the present study, the number of assigned primary nurses might also have been a measure of lack of organisational acknowledgement of FCC. In FCC, the focus shifts from disease alone to patients as part of family systems, requiring a nursing perspective where communication with families is a given priority. The system of assigning a named nurse to each family, in order to decrease the fragmentation of the nurse–family relationship, was established in this NICU several years before 1998, and the registration of assigned primary nurses in kardex records was initiated with the purpose of measuring nursing care quality in the NICU. As did many NICUs during this period, the unit struggled to decide between adopting a task-oriented and a relationship-based model of nursing care. The NICAP model was initiated, requiring the adaptation of care to preterm infants’ sleep–wake periods. At the same time, ward rounds and medical examinations, such as x-rays and eye examinations, were scheduled events, not adjusted to infants or their families. The nursing culture might still have considered technical and medical skills most important, even if this view remained unspoken. In the present study, sicker, preterm infants were...
assigned nurses more frequently than term babies, probably since they required more medical and technical attention. The relational tasks required of primary nursing might, therefore, have had a somewhat lower status. This contrasts with how parents describe their views of staff competency and the high value they place on caring behaviours involving learning to share responsibilities with families.

In a study from the US, where nurses in a 32-bed special care nursery rated reasons for the selection of primary patients, the most important factor was an infant’s medical problem, followed by continuity of care. Nurse–family relationships probably got off to poorer starts when there were no admission interviews and, hence, no nurse assessments based on families’ strengths and difficulties. Leaving families without primary nurses would have decreased support for collaborative nurse–mother/family relationships during the vulnerable period when mothers and families seek to establish a sense of ownership of their babies. In the special care nursery, impression of the family was rated only the third factor in the selection of primary patients, which might illustrate that an FCC philosophy of care did not entirely permeate nursing care at this facility.

As a challenge for task-oriented NICU environments and an opportunity to improve nursing care, an FCC nursing strategy should be implemented. This would fit with the development of single family rooms and kangaroo care around the clock in NICUs today in Sweden.

**Implications for clinical practice and future research**

This study was based on the assumption, from the 1970s, that increasing the frequency of assigned primary nurses in NICUs increases the quality of FCC nursing care. FCC, as a whole-care concept, has been shown to shorten hospital stays and decrease short-term morbidity for preterm infants. However, the role of nursing organisation, per se, in this context has, to our knowledge, not explicitly been studied in terms of quality of nursing care. The results of the present study indicate that the disease-focused perspective was the predominant base from which nursing leaders allocated primary nurses to families. As a consequence, only 36% of families had discharge notes transferred to their primary health care providers, discontinuing care planning and follow-up nursing care. Whether more family-focused nursing organisation, now entering the NICU scene, increases the quality of nursing care for patients and families remains to be studied. Future research should also address the impact of NICU nurse educational level and nurse work environment on primary nursing and family-centred NICU care quality.

If FCC is the basis for nursing, focus on primary nurse–family relations should move towards the health of entire families. This could induce nurse managers to schedule primary nurses for all families, not just those with the sickest babies, and, hence, increase the quality of care for all families.
Conclusion

Assigning primary nurses to families increases the likelihood of both admission interviews being conducted at the start of NICU stay and discharge notes being written at the end of NICU stay, making visible that nursing care plans have been implemented and that follow-up plans have been forwarded to primary health care providers. More effort should be made to increase the prevalence of assigned primary nurses and to further study whether this is a determinant of nursing care quality.

References


New perspectives on the contribution of digital technology and social media use to improve the mental wellbeing of children and young people: a state-of-the-art review

Andrew Clifton *
Senior Lecturer in Mental Health Nursing, Northumbria University, Coach Lane Campus East Benton, Newcastle upon Tyne, NE7 7XA, UK
Tel 0191 215 6114  Fax 0191 214 6082  Email a.v.clifton@northumbria.ac.uk

Deborah Goodall
School of Health, Community & Education, Newcastle upon Tyne, UK

Sasha Ban
School of Health, Community & Education, Newcastle upon Tyne, UK

Eileen Birks
School of Health, Community & Education, Newcastle upon Tyne, UK

*Corresponding author

Abstract
Objective The purpose of this paper is to identify the extent, if any, that digital technology can impact on the mental well being of children and young people, to determine some implications for practice, and to highlight any risks and/or barriers that may impede the use of such technology.

Methods This study uses a ‘state of the art’ literature review methodology to achieve this objective. Structured searches for 1980-2012 were conducted in three major subscription bibliographical databases, (Web of Knowledge, CINAHL and Proquest Nursing and Allied Health Source) during March 2012 by an Information Specialist working in partnership with the research team to identify English-language articles in press or published in peer-review academic journals.

Results A state of the art literature review identified 21 papers from Europe, North America and Australia. All of the included studies are tabulated to some extent and themes and key issues identified and narrated through the lens of the state of the art review. Six themes emerged from the data synthesis. 1) Risks and benefits of digital technology, 2) Health support, information and self-assessment 3) Iatrogenesis of digital technology 4) Health seeking and support, 5) Modes of digital therapeutic support and 6) Robotics, resilience and enabling technologies.

Conclusions There appears to be some benefits for some children and young people who use digital technology and social media to enhance their mental wellbeing, however, similar approaches could have a counter-productive effect. Collaboration to develop, design and undertake rigorous research around technological interventions would further enhance the evidence base for these approaches.

Keywords Digital technology, social media, children and young people, mental health.

What is known about this topic
- Worldwide children and young people are engaging with digital technology for leisure, education and communication purposes. Increasingly mental health practitioners are turning their attention to the use of such technology to enhance the mental well being of many young service users who can access these latest developments.

What this paper adds
- This state of the art review has uncovered a plethora of issues relating to the use of digital technologies to enhance the wellbeing of children and young people. There appear to be both benefits and disadvantages of using digital technology and social media to promote mental well being in young people. Despite these advances more rigorous research is required to further enhance the evidence base for these approaches.
Declarations
Competing interests Nil.

Funding Nil.

Ethical approval Not required.

Guarantor AC.

Contributorship Concept of study – AC, SB and EB; methodology – DG; data collection – AC, SB and EB; technical support – AC, DG, SB and EB.

Acknowledgements None.

Introduction
Young people account for 27% of the world's population and in any given year 20% of adolescents will experience a mental health problem, most notably anxiety or depression; however, this risk is increased by experiences of violence, humiliation, devaluation and poverty. Despite progress in identifying risk factors and effective interventions for treating mental illness in young people, a lacuna remains in how to prevent mental illness and promote positive mental health outcomes. The World Health Organization (WHO) highlights the importance of building life skills and providing psychological support in schools and other community settings for children and adolescents. In addition, the WHO has produced a document for policy makers, decision makers and programme managers in both developed and developing countries to improve the quality and “friendliness” of health services for young people. A central feature of the document is the “critical role” individual young people can make to their own health and wellbeing. Therefore, the identification, assessment and treatment of young people is a multidisciplinary endeavour dependent on the cultural, political and economic factors of the associated region, nation state or community.

One emerging paradigm that may have the potential to add to the identification, prevention and treatment of young people with mental health problems is the increasing use of digital technologies, including the internet and social media. The latest data from December 2011 indicates there are 2.2 billion (32.7% of the global population) internet users, a 528% growth rate since 2000. The growth in some regions such as Africa (2,988%), the Middle East (2,244%) and Latin America/ Caribbean (1,205%) is even more impressive and, according to Chan and Fang, new communication technologies will have a more significant impact on the lives of young people than other past technological innovations. Access to digital technologies among children and young people is dependent on a number of factors including age, gender, and socio-economic status and while it is acknowledged there is a vast digital divide among children and young people in both developed and developing countries, undoubtedly there is an opportunity to utilise digital technologies to promote and improve the mental wellbeing of children and young people. Despite these perceived opportunities, Seylwn offers a note of caution against popular assumptions that young people are intuitively expert users of digital technologies. Added to this caveat are potential safety issues, such as harassment, that may occur when children and young people access online resources.

Patel highlights the problem of categorising childhood and adolescence in different cultures globally. A cut-off from childhood status may occur in some cultures when a child becomes able to contribute socially or economically to their family. For example, a child of six years of age who begins working is no longer considered to be in childhood. Adolescence is similarly difficult to compartmentalise depending on context and culture with this stage ranging in ages from 12 to 24 years. In addition to the difficulties in defining the age spectrum, there is the added complexity of the possible non-linear aspect of child development dependent on environment.

Piaget's concepts of cognitive psychology and cognitive development provide insights into emotional development in childhood, highlighting how children's thinking differs from adult thinking. Adolescents possess a variation in coping levels – some recover better than others from stressful life events. Encouraging resilience is thought to be preferable to reacting after an event. Emotion-focused strategies, used for managing feelings, are used more frequently as the child grows into adolescence and problem-focused strategies are not thought to be related to age at all. It is important to acknowledge that these categories are socially constructed, when developing treatment modalities and innovative interventions to enhance the mental wellbeing of children and young people.

Aims and objectives or purpose
The purpose of this paper is to identify the extent, if any, that digital technology can impact on the mental wellbeing of children and young people, to determine some implications for practice, and to highlight any risks and/or barriers that may impede the use of such technology.

Methods

Approach

Synthesising evidence, by bringing together a range of individual qualitative and quantitative research reports that have a shared focus, can provide a fresh insight into a topic and lead to conceptual development. This study uses a state-of-the-art literature review methodology to achieve this aim. The strength of such a literature review lies in its ability to address more current matters in contrast to other combined retrospective and current approaches, and as such it may offer new perspectives on an issue or point out areas for further research. As with, for example, a systematic review, the research question is identified, relevant studies are found through comprehensive searching of current literature and considered for inclusion/exclusion. However, at this point there is no formal quality assessment; selection criteria are not based on the quality of the studies but on relevance to the topic. All of the included studies are tabulated to
some extent and themes and key issues identified and narrated through the lens of the state-of-the-art review. The concluding analysis reflects the current state of knowledge and identifies priorities for future investigation and research.

**Identification of relevant studies**

Structured searches for 1980–2012 were conducted in three major subscription bibliographical databases (Web of Knowledge, CINAHL and Proquest Nursing and Allied Health Source) during March 2012 by an information specialist (DG) working in partnership with the research team (AC, SB, EB) to identify English-language articles in press or published in peer-reviewed academic journals. The following search terms and variants were applied: (child* OR "young people" OR "young adult"* OR adolescen* OR teenage* OR paediatric*) AND (mental health) AND (issue* OR problem* OR illness* OR risk* OR condition* OR difficult*) AND ("social media" OR "social network"* OR internet OR computer* OR online OR "mobile technolog*" OR "information communication technolog*" OR ICT). A search of selected professional websites (MIND, NHS Evidence, NSPCC, SCIE, UNICEF, WHO) was also made in order to retrieve relevant grey or unpublished literature. This hand search identified four items that matched the screening and selection criteria. References of the full-text articles assessed for eligibility were hand-checked to identify further references that satisfied selection criteria.

**Screening and selection for eligibility**

A total of 620 references (196 from Web of Knowledge, 297 from CINAHL, 127 from Proquest Nursing and Allied Health Source) were retrieved and downloaded into an EndNote 14 Library. References dating from pre-2000 were removed.

![Diagram 1. Summary of identification, screening and selection process.](image)
Duplicate references, foreign language items, references that referred to papers that were not in press or published in a journal (for example, dissertation abstract, conference abstract and so on), or did not report original research (for example, review papers) were excluded by DG. The remaining 521 references were screened independently at title/abstract level by DG and by AC working to the following criteria to identify items that focused on these three aspects in combination: "young people", for example, of school/college/university age, any mental health issue, the use of digital technology by the young people in connection with the mental health issue. Four hundred and ninety-nine digital technology by the young people in connection with the internet use such as cyber-bullying. Full-text articles were obtained for the remaining 22 references and these were then shared between the team members (AC, SB, EB) and assessed for eligibility using a derivation of the Open University’s PROMPT (Presentation, Relevance, Objectivity, Method, Provenance, Timeliness) checklist for considering evidence\(^\text{13}\). We attempted to map all PROMPT categories to the studies reviewed; however, this was not always possible as each study included did not contain all categories. Five full-text articles were excluded and these are listed, together with exclusion reasons in Box 1.

**Box 1. Excluded references.**

<table>
<thead>
<tr>
<th>Reference</th>
<th>Reason for exclusion</th>
</tr>
</thead>
</table>

**Walsh JV, Scaife et al. Perception of need and barriers to access: the mental health needs of young people attending a Youth Offending Team in the UK.** Health Soc Care Community. 2011;19(4):420–428. **This study is about barriers and access to services, not social media or technology.**

The characteristics and key findings of the articles that satisfied the selection criteria and are included in the review are shown in Table 1.

### Results

#### Themes and key issues

**Risks and benefits of digital technology**

Children’s use of the internet is often associated with a degree of risk as shown by all of the findings reported in Table 1. The risks include cyber bullying\(^{14,15}\), sexual exploitations, for example "sexting"\(^{15}\); and psychological ill health including Facebook depression\(^{15,16}\), social anxiety and loneliness\(^{17}\). Devine and Lloyd\(^{14}\) identify that girls are affected more than boys. In addition, Wells\(^{18}\) suggests internet use appears to affect academic competence and performance in a school setting. Reported problems included issues around truancy, online harassment by peers and inappropriate use of school computers to access pornography. McBride\(^{15}\) adds that the age of children and their susceptibility to peer pressure puts them at greater risk when navigating the internet and Borzekowski\(^{16}\) notes that online media literacy skills should not be assumed. Despite the obvious hazards of internet use, McBride\(^{15}\) stipulates that there are benefits including enhancing communication, broadening social connections and learning technical skills.

**Health support, information and self-assessment**

The internet is widely used as a “health-seeking” tool\(^{16,19,20}\). This appears to be an age-related concept and the older adolescent is more likely to utilise the internet in this way\(^{20}\). Using the internet as a health information source can be seen as low in cost and anonymous\(^{20}\), but this needs to be carefully balanced against the possible harmful effects. Health advice for one young person could be construed as ill-health for another\(^{19}\). As gatekeepers, health professionals should be aware of this dichotomy\(^{19}\) and seek to undertake naturalistic research to examine internet usage and experiences in order to measure the effects on health, knowledge and behaviours in children and young people\(^{19}\).

**Iatrogenesis of digital technology**

Internet use can be the root cause of psychological issues in young people\(^{21}\). It is also an extension of pre-existing behaviours and emotions that clinicians had already identified and were treating such as victimisation and isolation\(^{21}\). However, Gowan and Descahaine\(^{22}\) argue that there is a place for the internet, particularly social networking sites, to lessen isolation for those with existing mental health issues. Of prime importance is the issue that practitioners working with clients should ask clients about their internet access to social networks.
<table>
<thead>
<tr>
<th>Reference</th>
<th>Main findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Borzekowski DLG. Adolescents' Use of the Internet: A Controversial Coming-of-Age Resource. Adolesc Med Clin. 2006;17(1):205–16.</td>
<td>A discussion paper which highlights the need for young people to develop online media literacy skills to negotiate around website in relation to mental and psychiatric conditions. More research is required to determine the efficacy of online therapies and health promotion sites. Age range: young people (not specified).</td>
</tr>
<tr>
<td>Burns JM, Durkin LA et al. Mental health of young people in the United States: what role can the internet play in reducing stigma and promoting help seeking? J Adolesc Health. 2009;45(1):95–97.</td>
<td>This paper reviews an Australian, internet-based service (Reach Out) to determine its usefulness in reducing stigma and increasing self-help for young Americans. The results identify that Reach Out had increased awareness of support, conditions and how to help others in relation to their mental wellbeing. Age range: 16–25.</td>
</tr>
<tr>
<td>Chisolm DJ, Gardner W et al. Adolescent Satisfaction with Computer-Assisted Behavioural Risk Screening in Primary Care. Child Adolesc Ment Health. 2008;13(4):163–168.</td>
<td>A research study which explores the satisfaction rates of young people with a computer-assisted screening tool for &quot;risk behaviour&quot;. The time-efficient computerised screening tool used in primary care has the potential to improve screening and in this study was perceived to be useful and easy to use. Age range: 11–20 years.</td>
</tr>
<tr>
<td>Cleary P, Walter G. Is e-mail communication a feasible method to interview young people with mental health problems? J Child Adolesc Psychiatr Nurs. 2011;24(3):150–2.</td>
<td>Use of ICT for confidential email interviews highlighted in this study. It was felt that not being &quot;face to face&quot; allowed for greater exploration of sensitive issues. Age range: not specified.</td>
</tr>
<tr>
<td>Devine P, Lloyd K. Internet use and psychological well-being among 10-year-old and 11-year-old children. Child Care in Practice. 2012;18(1):5–22.</td>
<td>An annual quantitative survey documenting social issues affecting the lives of young people in Northern Ireland particularly looking at internet use and psychological wellbeing. The KIDSCREEN-27 instrument was used to assess quality of life as reported by the child. High use of ICT was reported, and the use of social networking sites and online games related to poor psychosocial wellbeing in girls but not boys. Both boys and girls who experience cyber-bullying had poorer psychosocial wellbeing. Age range: 10–11 years.</td>
</tr>
<tr>
<td>Gowen K, Deschaine M et al. Young Adults with Mental Health Conditions and Social Networking Websites: Seeking Tools to Build Community. Psychiatr Rehabil J. 2012; 35(3):245–250.</td>
<td>This research study highlights the need for practitioners to be aware of, and safely encourage use of, different social networking sites used by young adults living with a mental health illness. Particular interest was said to be shown by that group, in websites tailored to their population with tools to decrease social isolation and aid independence. Age range: 18–24 years.</td>
</tr>
<tr>
<td>Gross EF, Juvonen, J, Gable, SL. Internet use and well-being in adolescence. J Soc Issues. 2002;58(1):75–90.</td>
<td>The hypothesis that internet use may be associated with decrease in wellbeing in adolescence is challenged in this paper. The association between wellbeing and social aspects of internet use is examined here, using “dispositional measures of wellbeing” and also logging of instant messages. The latter was associated with daily social anxiety and loneliness in school, but time spent online was not associated with dispositional or daily wellbeing. Age range: not specified.</td>
</tr>
<tr>
<td>Horgan A, Sweeney J. Young students’ use of the Internet for mental health information and support. J Psychiatri Ment Health Nurs. 2010;17(2):117–123.</td>
<td>A solution to the perceived issue of stigma by young people to accessing mental health services is addressed in this quantitative study. It suggests offering support by psychiatric nurses on the many websites available offering information on mental health issues. One-third of the participants had searched the internet for information on depression and the majority would have preferred face-to-face support. Age range: university students.</td>
</tr>
<tr>
<td>Mackenzie R, Watts J. Robots social networking sites and multi-user games: using new and existing assistive technologies to promote human flourishing. Tizard Learning Disability Review. 2011;16(5):38–47.</td>
<td>Speculates on how future technologies, such as robotics, can enable and assist young people (and into their older age) to enhance their wellbeing in the form of emotional companionship, communication and reducing isolation. Age range: 10-plus.</td>
</tr>
<tr>
<td>Mitchell KL, Finkelhor D et al. Linking youth Internet and conventional problems: findings from a clinical perspective. J Aggress Maltreat Trauma. 2007;15(2):39–58.</td>
<td>Study looked at linking youth internet and conventional problems from a professional perspective. Cluster analysis identified “online victimisation”, “inappropriate sexual behaviour”, “online isolation” and “online/offline problems”. Problematic internet experiences are often behaviours clinicians were already working with prior to the advent of the internet, but there was increased severity and frequency of problems requiring “unique responses”. Age range: 5-plus</td>
</tr>
<tr>
<td>Murie J, Dickson, A. Think positive: a mental health promotion website for 12-18 year olds. Int J Ment Health Promot. 2002;4(1):26–33.</td>
<td>This paper describes the development of a mental health promotion website. Its place in clinical practice is dependent on whether its information is accurate and access is secure. Guidelines are recommended. Age range: 12–18 years.</td>
</tr>
</tbody>
</table>
### Health seeking and support

Horgan and Sweeney\(^26\) found that a large number, 30.8% of the 18–24 year olds in their study, used the internet to seek advice about mental health issues, predominantly depression and they allude to the idea that accessing mainstream mental health services has stigma attached. Furthermore, Murie and Dickson’s initiative\(^27\) adds to this perception in relation to the adolescent aged 12–18 years; they argue that there is definitely a place for this type of advice. They urge that the information provided is accurate and reliable, that access should be secure and confidential, and that the design is acceptable to users. Importantly, they stress this development is supported by health service staff and professional bodies\(^27\).

#### Modes of digital therapeutic support

An Australian service provides an online community forum\(^26\), which aims to increase mental health literacy, reduce stigma and promote help seeking\(^28\). Penn\(^31\) also developed a similar online support for children over 13 years of age who lived in rural and remote environments in Australia. Geographically this group of children and young people required an alternative mode of support. Anonymity and confidentiality were seen as important elements of success in supporting young people with mental health issues in both of the above studies\(^28\).\(^31\). Furthermore, the anonymity issue was raised by Cleary and Walker\(^32\) who identified that investigative enquiry into sensitive issues such as mental health are often more successful via email than face to face.

#### Robotics, resilience and enabling technologies

Stephens \textit{et al.}\(^33\) state that the innovative use of digital

---

### References


One in three Australians have used the website Reach Out! since 1998. This case study concluded it can serve as a model for the social sector to use ICT to promote mental health and wellbeing of young people. Age range: not specified.


This research study involved telephone interviews to compare young people’s preferences for mental health help: self-help books or counselling with mental health input. Vignettes were used and the low cost and anonymous method of receiving information was particularly important for young people. Age range: 12–25.


Children of war veterans have a higher risk of suicide. This participatory action research evaluates online support for vulnerable young Australians. The facility allowed online discussion and access to information about Australia’s involvement in the Vietnam War. Technologies used built a sense of trust and shared identity with anonymity among the users, providing an alternative to face-to-face services for rural areas. However, a selection of ‘emoticons’ were added by web developer to alleviate lack of facial gestures. Age range: 13.


School staff, primary care and youth services are more likely to act as gatekeepers to mental health services for young people. They are increasingly using internet-based interventions to assist with self-help. Age range: 16–25.


This research study looks at a school-based website and notes its promise for self-identification of emotional problems. Age range: not specified.


This descriptive account highlights challenges to ICT-based health services. These include inadequate access and training, lower literacy levels and the need for specialised technologies for people with disabilities. Age range: 14–25.


An option for identification of psychosocial problems in children is described through the use of the simulated “item response theory-based computer adaptive test” (IRT-CAT). It was found to lead to efficient, high-quality identification of psychosocial issues; however, the results need to be replicated in real-life simulation. Age range: 14–24.


Australian study examining the Reach Out! programme to bridge the gap between those experiencing mental health difficulties and those seeking help. Programme is underpinned by youth involvement and promotes help seeking and reduction of stigma. Age range: not specified.


Study of social workers in the USA, exploring their levels of awareness of internet-related problems children experience. Internet-related problems affect youth social and academic competence and performance in the school setting. Age range: not specified.
technology can be beneficial to the mental wellbeing of children and young people. Digital technology programs can promote resilience, providing they consider the literacy levels of children and young people. There is evidence that Sentient Robots (with social, emotive and cognitive abilities) have a place in daily life, enhancing wellbeing in the form of emotional companionship, communication and reducing isolation.

**Discussion**

Children and young people are engaging with digital technology on a daily basis and this is a worldwide phenomenon. Although there is variance internationally in the utilisation, it is clear that this exponential growth is a feature that cannot be ignored in society. Children and young people use this technology as a means of recreation and education; consequently it is an area ripe for development. This state-of-the-art review illustrates the use of digital technology as an emerging paradigm in the mental wellbeing of children and young people.

There are documented risks and benefits of digital technology use in the literature. These can range from affecting school performance, increasing loneliness and social anxiety, to enhancing communication and broadening social connections. Cognisance should be given to the fact that girls appear more affected than boys. Children from the same chronological age groups can draw different conclusions from digital information. Therefore, assumptions should not be made regarding children's developmental stage and literacy level. The development of a regulatory 'safety net' should be considered when children and young people navigate the 'high wire' of the digital world.

Health promotional advice is readily available via a range of media including online support and mobile telephone applications. These approaches are valued for their perceived anonymity and low cost and are frequently used by the adolescent age group. Harmful effects, however, have been noted in the literature where self-help strategies for one individual may not be effective for another. One size cannot fit all and information needs to be tailored to the individual young person and in their cultural context. This is a challenge for digital technology where self-assessment and self-help are requested. More research is required to measure the effect on health outcomes in children and young people using technologies for mental wellbeing.

Using digital technology for information concerning the mental health issue of depression is common among young people aged 18–24 years. Mainstream, face-to-face contact is felt to have a stigma attached and so advice via technological media certainly needs to be available. However, to have any benefit to young users, it is essential that any design must contain up-to-date, credible information while being secure and confidential. Professional organisations should recognise that these features need to be in place to ensure effective mental health support and trust in the technological source.

Flexible approaches to digital technologies are required to ensure maximum access by children and young people in need of mental health support. These alternative modes of support should extend across geographically diverse locations. Variability in approach and consideration of developmental stage is also important with digital technology. Younger children often seek affirmation and help around emotional issues from family members. However, adolescents, in the formal operational stage of cognitive development, may seek mental health support online from peers (social media) as well as digital technology in the form of interactive games, but not from family members. A move from family support systems to digital systems for mental health promotion in adolescence is an issue that families and health professionals need to acknowledge.

Innovative use of digital technology can benefit mental wellbeing including the promotion of resilience in children and young people. Devices such as mobile phones and laptop computers may become objects of attachment, as they can provide access or escape in some cases, to virtual realities. Digital technology such as Sentient Robotics may be perceived by children and young people as an ideal set-up for them, and may provide companionship and lessen feelings of isolation. Harnessing this resource for the purpose of prevention and treatment of mental illness seems like an innovative and interesting development in the future.

**Limitations**

The small scope of this review is a limitation. Studies included in the review were from Europe, North America and Australia and it could have benefited from studies undertaken in other geographical locations. Due to time constraints, only a selection of resources could be searched for evidence. This is clearly an area where published literature lags behind practice and the pace of technological development is often startling. Although many children and young people in developing countries have access to the latest technology, many of these countries do not have the human and service resources to capitalise on these latest innovations.

**Conclusion**

This state-of-the-art review has uncovered a plethora of issues relating to the use of digital technologies to enhance the wellbeing of children and young people. There appear to be some benefits for some children and young people who use digital technology to enhance their mental wellbeing; however, similar approaches could have a counter-productive effect. The potential for iatrogenesis needs to be considered by both practitioners and young people as there are implications that some digital technological interventions may do more harm than good. Despite this note of caution, we recognise there are benefits to this approach and recommend practitioners and service users ensure they engage with reliable and valid technological tools. Collaboration to develop, design and undertake rigorous research around technological interventions would further enhance the evidence base for these approaches.
Implications for clinical practice

As advances in technology continue at an ever-increasing pace around the world, it is vital that there is contemporaneous advancement in the practitioners’ awareness of the wide-reaching scope of digital technology when working in the field of children and young people’s mental health. It is acknowledged that internationally, childhood is difficult to define and when planning age-appropriate digital resources for self-assessment and help, caution must be exercised, as it is clear that one size does not fit all. Practitioners need to have detailed knowledge of child development theory and awareness that the widespread use of technology often begins in the pre-school years. The digital navigation skills of the young service user can outstrip those of the practitioners developing interventions aimed at offering mental health help. There can be a discontinuity in digital knowledge between practitioner and the young person; however, there can also be a digital divide within the young population itself; therefore, consultation and collaboration may be one way forward, incorporating the additional help of software designers.

Involvement of young service users as partners in their care is a popular movement and this should be capitalised on when planning service developments around this age group. Reminders for appointment times and prompts for timing of medication via text are already used in practice in some countries and where this is established, incremental use of digital technology should be considered in partnership for mental health support. The economic responsibilities some children have, can limit their opportunities to seek help by conventional means and they may access digital technology for a range of mental health issues. These would need to be easily accessible and informative. Others may desire a more nurturing but anonymous approach to their mental health issues and consequently practitioners can provide sensitively attuned but factual information.

References

What is a Cochrane Review?

Cochrane Reviews help us to ‘make sense’ of often large amounts of evidence for and against health care treatments and practices. They are specifically designed to help clinicians, patients and policy makers make choices regarding health care interventions. Most Cochrane Reviews are based on randomised controlled trials, but other types of study designs may also be taken into account.

Cochrane summaries are based on new and updated systematic reviews published in The Cochrane Library. The summary must be read in conjunction with the full review when making decisions. The authors’ conclusions are summarised but have not been reinterpreted.

How do I access the full review?

Complete reviews are published monthly by the Cochrane Library and are available at http://www.thecochranelibrary.com/

Cochrane Review Summary: Sedation of children undergoing dental treatment

Cochrane summaries are based on new and updated systematic reviews published in The Cochrane Library. The summary must be read in conjunction with the full review when making decisions. The authors’ conclusions are summarised but have not been reinterpreted.

Clinical context

Despite reductions in the incidence of dental caries in industrialised countries, a high percentage (up to 39%) of children have untreated dental caries. Untreated caries lead to pain, sepsis and extraction of the affected tooth. Children’s fear of dental procedures has led to the use of general anaesthetics for childhood caries; however, use of these anaesthetics has potential serious health consequences and service costs. Common barriers to treatment using local anaesthetic are fear and behaviour management problems. Sedation is an alternative to general anaesthesia that reduces anxiety and improves behaviour, allowing the treatment to be performed and resulting in a positive childhood experience.

Conscious or moderate sedation, for this review, was one in which the child could independently keep their mouth open, retain their protective reflexes, and respond to verbal commands reliably. Benzodiazepines, nitrous oxide and other agents were included in different combinations, delivery methods and doses, and sometimes physical restraints were used.

The aim of this Cochrane review was to determine which sedative agents were effective to control problematic behaviour in children receiving dental care.

Methods

Inclusion criteria

Studies

Randomised controlled clinical trials, including cluster randomisation.

Participants

Age: children between 0 and 16 years.

Dental procedures: simple restorative treatment with local anaesthesia (for example, fillings, stainless steel crowns), simple extractions or management of dental trauma (for example, repositioning of a tooth, splinting, removal of a nerve from a tooth).

Intervention

Any sedative agent (causing conscious, not deep sedation) administered by a dentist or dental team in either an outpatient or dental office setting. Studies compared either active treatment and placebo, different doses or routes of administration of the same sedative, or different sedatives. Sedatives were delivered orally, intranasally, intravenously, rectally, intramuscularly, submucosally, transmucosally or by inhalation by a dentist or dental team in either an outpatient or dental office setting.

Outcomes

The primary outcome was behaviour. Secondary outcomes included treatment completion, postoperative anxiety and adverse events.

Results

Of the 159 studies identified, 36 studies from 13 countries met the inclusion criteria. There were 2810 children included in the review with a mean number of 78 per study, with a mean age of 4.7 years. Most were uncooperative or anxious at the beginning of their treatment. Twenty-eight different sedatives were used with or without nitrous oxide with wide variations in dose, mode and time of administration.
All 36 studies meeting the inclusion criteria were included irrespective of quality. High risk of bias was found in at least one area in the majority of trials (83%, n=30), and unclear risk of bias was found in 17% (n=6) trials.

Meaningful data were only available on behavioural differences, and postoperative anxiety was rarely measured. Participants completed treatment in most studies and, although adverse events were recorded, this was not in a standardised manner. Use of a restraint system and nitrous oxide in conjunction with the main sedative were reported in some studies.

Placebo controlled trials (9) showed weak evidence that oral midazolam improved children's behaviour – relative to dose (standardised mean difference 2.98, 95% confidence interval (CI) 1.58 to 4.37, p<0.0001), with few adverse effects reported. Nitrous oxide showed weak positive effects and no adverse effects. Dose controlled trials (7) showed weak evidence that oral midazolam (0.5–0.75 mg/kg) was effective in improving children's behaviour and there were conflicting results from studies evaluating intranasal midazolam.

Significant adverse effects were associated with chloral hydrate, specifically airway issues, especially with high doses (>50 mg/kg) combined with inhaled nitrous oxide.

**Authors’ conclusions**

**Implications for practice and further research**

There was weak evidence from five trials that oral midazolam is an effective agent for conscious sedation for children undergoing dental procedures. Nitrous oxide demonstrated very weak evidence of effective sedation. There is a need for well-controlled studies using the CONSORT guidelines, particularly with midazolam and nitrous oxide. Quality research is needed with specific recommendations: blinding of the operator, patient and assessor; samples based on sample size calculations and in age brackets; only parallel study designs conducted. Baseline and outcome variables must become patient-centred, for example, patient satisfaction, anxiety, and patient perception and include measures of anxiety, completion for treatment and patient satisfaction/preference. Reporting of deep versus conscious sedation and sleeping is essential.


Review content assessed as up-to-date: 13 January 2012.
Special Issue November 2013 –
CALL FOR PAPERS

Health promotion or harm minimisation for children and young people has an important role in policy and practice. This special issue aims to explore this topic in relation to community and acute initiatives, service delivery and policy within the contexts of infants, children and young people. The special issue will be published in November 2013.

We welcome a broad spectrum of scholarly papers, based on research, systematic review or service evaluation, that extend the knowledge base of effective health promotion and are relevant to nursing practice for this group.

Topics may include the following, although this list is not exhaustive:

- Models/frameworks for health promotion care for children and young people
- Outcomes of acute or community care
- Prevention and population health
- Promoting healthy lifestyles
- Supporting children and young people with chronic disease

All papers should be submitted through the Cambridge Manuscript Management System and the standard guidance for authors should be used: http://www.npchn.com/

We ask all authors to identify the paper as being for the health promotion special issue by using the initials “HP” in the title of their paper (e.g. “HP: The role of the school-based counsellor in early identification of mental health issues”).

The deadline for receipt of papers is 26 April 2013.

All papers will be subjected to the journal’s usual double-blind peer-review process as set out in the guidance for authors. Should there be too many papers accepted following peer-review for the space available in the special issue, then these papers will be published in subsequent issues of Neonatal, Paediatric and Child Health Nursing.

Associate Professor Jodi Shaefer, Guest Editor, and Professor Linda Johnston, Editor

Online submission
Submit your paper to Neonatal, Paediatric and Child Health Nursing: http://www.npchn.com/
NEW KNOWLEDGE, NEW CARE

REGISTER ONLINE BY FRIDAY 7 JUNE 2013 TO SECURE THE EARLY REGISTRATION FEE

THE COUNCIL OF INTERNATIONAL NEONATAL NURSES: 8TH INTERNATIONAL NEONATAL NURSING CONFERENCE 2013

Belfast, Northern Ireland 5th - 8th September, 2013

ABSTRACT SUBMISSION CLOSES ON 5 APRIL 2013
Take the opportunity to submit for both oral and poster presentations

VISIT THE NEW WEBSITE AT: www.coinn2013.com