DOI: 10.1097/JPN.0000000000000020

**CE** **Continuing Education**

*J Perinat Neonat Nurs* • Volume 28 Number 4, 280–289 • Copyright © 2014 Wolters Kluwer Health | Lippincott Williams & Wilkins

# A Descriptive Study Evaluating Perinatal Healthcare Providers' Perspectives of Palliative Programming in 3 Canadian Institutions

Simone J. Stenekes, RN, MN, CHPCN(C); Carla D. L. Ens, BEd, BHEc, MSc, PhD;
Michael Harlos, MD, CCFP, FCFP; Harvey Max Chochinov, PhD, MD, FRSC;
Kristine Mytopher, MD, FRCSC

## ABSTRACT

A paucity of research has evaluated the perspectives of the broader healthcare team regarding perinatal palliative care. This study examines the views of healthcare providers involved in perinatal palliative care in 3 tertiary care hospitals in Canada. Developing an understanding of their perspectives of care provision, as well as the interactions that took place with families and other teams while providing perinatal palliative care, was of interest. Twenty-nine healthcare providers were involved in 4 focus groups and 5 individual interviews. Data were transcribed and content analysis was undertaken. The overarching theme of communication materialized from the data. Within this theme were 3 subthemes, each highlighting an aspect of communication that impacted care provision: connecting through proximity, protected time and dedicated space, and flexibility and formality. The study also describes a model of integrated perinatal palliative care program development and explains where each of the 3 sites falls along this continuum. The development of formal programs in these facilities is varied and recommendations are included to enhance communication and assist in providing improved and integrated programming.

**Key Words:** perinatal hospice, perinatal palliative care, program development

In the developed world, more children die immediately prior to birth or in the neonatal period than at any other time in childhood.[1,2] Perinatal palliative care (PPC) (also referred to as perinatal hospice) is defined as the care provided to families and infants in the perinatal period including any point in time prior to birth and during the newborn or infancy stages.[3] In addition to the mandate of ensuring comfort for dying infants, the 2 general tenets of PPC are to help families with the process of making choices about pregnancy management and afterbirth care, and to ensure that choices are both consistent with families' personal beliefs and in the best interest of the infant.[1] Perinatal palliative care affirms life; regards dying as a normal process; stresses values that go beyond the physical needs of the infant and the family; meets the medical, emotional, and spiritual needs of the family; and neither hastens nor prolongs death.[4–8]

---

**Author Affiliations:** Transition & Palliative Care, CancerCare Manitoba, Winnipeg, Manitoba, Canada (Ms Stenekes); Manitoba Health, Winnipeg, Manitoba, Canada (Dr Ens); Winnipeg Regional Health Authority Palliative Care Program, Winnipeg, Manitoba, Canada (Dr Harlos); Manitoba Palliative Care Research Unit, CancerCare Manitoba, Winnipeg, Manitoba, Canada (Dr Chochinov); and Department of Obstetrics, Gynecology and Reproductive Sciences, University of Saskatchewan, Saskatoon, Saskatchewan, Canada (Dr Mytopher).

This research is financially supported by The Innovation Fund in Children's Palliative Care Research from The Team for Research with Adolescents and Children in Palliation and Grief (TRAC-PG) at SickKids in Toronto, Canada. Dr Chochinov is a Canada Research Chair in Palliative Care, funded by the Canadian Institutes for Health Research (CIHR). The authors thank Katherine Cullihall and Devon Brown for their help with conducting the focus groups.

**Disclosure:** The authors have disclosed that they have no significant relationships with, or financial interest in, any commercial companies pertaining to this article.

**Corresponding Author:** Simone J. Stenekes, RN, MN, CHPCN(C), Transition & Palliative Care, CancerCare Manitoba, OG015—"O" Block-409 Tache Ave, Winnipeg, Manitoba, Canada R2H 2A6 (simonestenekes@gmail.com).

Submitted for publication: July 12, 2013; accepted for publication: December 23, 2013.

## LITERATURE REVIEW

Only recently has attention been given to the crucial palliative care needs within the perinatal population.[9] In circumstances of life-limiting conditions, the standard of care must include the options of termination of pregnancy as well as PPC.[10,11] When parents are provided full disclosure and informed counsel on what to expect in the setting of a life-limiting condition, 37% to 87% of parents chose PPC and they are generally satisfied with the care they receive.[12–16]

Advances in technology have expanded what can be known prenatally. However, prognostication for many life-limiting conditions remains uncertain.[6] During the prenatal period, parents desire early consultation,[17] detailed information, and support.[18] Although many of the needs of dying infants and families are known, too often healthcare providers (HCPs) fail to meet those needs,[2] and only a small portion of infants who die in the perinatal period receive services from a palliative care program.[19,20] Earlier referral may be required to provide comprehensive care.[21]

Despite published guidelines for care planning and symptom management in PPC,[3,5,22,23] implementation and improvement is required. When providing care to dying infants at birth, providers do not adequately document the symptoms experienced, nor are medications commonly used to manage symptoms that are present.[24,25] Valid and reliable instruments to measure respiratory distress,[26] lethargy, neuroirritability, and quality of life in this population are required in order to adequately assess and treat symptoms.[27] The evidence for most interventions in PPC is lacking; however, the management of symptoms at end-of-life is still required.[27]

Barriers faced by nurses providing PPC include the inability for the nurse to express personal opinions, values and beliefs regarding palliative care, a less than optimal physical environment, technological imperatives, parental demands, and lack of education for nurses in palliative care principles.[28–30] Facilitators for these nurses include a supportive medical staff, parents being informed of options and being involved in decision making, institutional policies to support palliative care, as well as time spent with the dying infant.[30] Measurement of the perceptions and barriers that HCPs have toward PPC is a first step to identifying program issues, interventions to modify the practice environment, and educational opportunities.[31,32] There is a paucity of research that has evaluated the perspectives of the broader healthcare team about PPC.[33] Information on individual PPC programs has only recently been described in the literature, and no published evidence-based empirical models exist.[14,34]

## PURPOSE

This study was undertaken to examine the views of HCPs involved in PPC. Developing an understanding of their perspectives of how they provided care, as well as the interactions that took place with families and other teams while providing PPC were of particular interest. In evaluating the data from participants as well as recommendations in the literature, a new model to guide PPC programming was developed.

## SETTING

In Canada, there are varying degrees of programming in perinatal and pediatric palliative care. The neighboring provinces of Saskatchewan (population 1 063 000) and Manitoba (population 1 225 000) were selected for this study in light of contrasting approaches and similar demographics. At the beginning of the study, a formal PPC program had yet to be initiated in Saskatoon, the province's largest city. The development of a formal program was being explored, and a pediatric palliative care physician was hired as the study concluded. In the province of Manitoba, the Pediatric Palliative Care Service was developed in late 2006 to provide consultation, leadership, and care. The majority of births that receive PPC take place in the 2 tertiary care hospitals located in the capital city, Winnipeg. Although the bulk of PPC programming is focused there, the program attempts to facilitate care regardless of location.

The study was based at 3 tertiary care hospitals: 1 in Saskatoon, Saskatchewan, and 2 in Winnipeg, Manitoba. *Site 1 (Saskatchewan)* is a tertiary care facility, which provides acute care services and is the province's main trauma center. The site has about 5200 deliveries per year. *Site 2 (Manitoba)* is the largest healthcare referral, teaching, and research center, serving residents of Manitoba, northwest Ontario, and Nunavut, and has about 5500 deliveries per year. *Site 3 (Manitoba)* is the second largest hospital in Manitoba, providing community outreach programs, ambulatory care programs, and inpatient services with approximately 5500 deliveries per year. All sites provide prenatal care, have a neonatal intensive care unit (NICU), and they all have pediatric tertiary facilities on-site or direct access to pediatric facilities.

## METHODS

### Design and ethical approval

This study used a qualitative descriptive design. Participants were involved in a focus group or individual interviews on 1 occasion. Ethical approval was granted by the Research Ethics Boards of the Universities of Manitoba and Saskatchewan, with access approval obtained from the 3 participating sites. Written informed consent was obtained from all participants. Participants were offered a small honorarium to cover expenses pertaining to transportation.

### Participant accrual and procedures

All staff of the 3 sites that provided direct patient care in any capacity to pregnant mothers or infants were eligible to participate. This included physicians, nurses, respiratory therapists, midwives, social workers, chaplains, ultrasonographers, and other HCPs in the settings described. Participants represented a variety of perinatal clinical care areas, which included fetal assessment, obstetrics, neonatology, the NICU, the nursery, the postpartum unit, high- and low-risk delivery units, as well as pediatrics and palliative care. Out of approximately 850 eligible staff, 29 participated in this study.

Accrual for participants utilized 2 methods. The initial method had participants identify an interest and contact the researcher. Posters and e-mail messages describing the study were utilized to recruit participants in this way. About half of the participants became involved in the study by this method of accrual. When additional participants in focus groups and interview were required, purposive sampling was utilized to obtain a representative sample of healthcare disciplines and clinical areas involved in PPC.[35] Focus groups were the primary method of data collection, allowing participants to collectively identify and discuss a multitude of topics.[36] The palliative care consultation team members were interviewed individually, as it was felt that their participation in a focus group could possibly alter the degree of comfort for the group when asked to comment on how palliative care services were provided. When the focus groups at site 1 did not provide adequate representation from a variety of clinical areas and disciplines, recruitment was targeted at specific departments to provide the broader perspective desired. Semistructured interviews were then conducted. These accrual strategies were undertaken to obtain a wide variety of perspectives and improve the trustworthiness of the data.

### Focus group and interview guide

A demographic form was used to elicit basic information from participants. A question guide, developed by the research team to elicit the perspectives of the HCPs regarding the delivery of PPC services, was used for all focus groups and interviews. Probing questions were used to obtain further detail on comments provided by participants. Four topic areas were incorporated into the guide: (1) education and work experience, (2) experiences with patients and other healthcare team members when providing PPC, (3) PPC approach within each institution, and (4) impact of providing PPC. In Manitoba, a fifth area pertaining to interactions with the formal palliative care program team was included. These questions were open-ended, intended to solicit information about processes and how the system of PPC delivery could be improved.

### Data collection

Each focus group had a leader (CE) and a recorder (varied by site). The leader asked the questions and engaged the group, while the recorder took notes pertaining to the overall process and content. Following each focus group, the leader and the recorder held a debriefing session to capture initial impressions and discuss emerging themes. Four focus groups were held in total. Two focus groups took place at site 1 (with 3 and 5 participants, respectively), with 1 focus group held at site 2 (8 participants) and 1 at site 3 (8 participants). Focus groups ranged in length from 48 to 100 minutes. Five individual interviews were conducted by a member of the research team (SS): 4 took place by phone and 1 was in person. Interviews were recorded and lasted 17 to 31 minutes in length. The interviewer took notes during and after the interviews.

To maintain confidentiality when direct quotations are used, the profession of the participant is not listed. Only the site where the individual works is identified. There were 3 individuals who acknowledged that they provided care at both site 2 and site 3. Therefore, these quotes are attributed to both sites.

### Analysis

A qualitative descriptive approach was used to capture the perceptions of HCPs and to better understand the experiences of professionals providing PPC. Content analysis was undertaken, which allowed for the development of a thematic summary, while maintaining the essence of participants' views and language.[36] The qualitative data were analyzed thematically, which involves an ongoing search for patterns within the data toward the formation of themes.[37] All focus groups and interviews were recorded and transcribed verbatim. Two authors (SS and CE) independently read through the transcripts and the extensive notes and summaries from the focus groups and interviews. The 2 authors met to discuss and develop content themes. Following this, all authors met to broadly discuss the themes and refine the model of program development. Transcripts were then coded by the primary author (SS) according to the themes and model.

## RESULTS

### Participants and demographics

Data collection took place over a period of 13 months, from June 2010 to June 2011. A total of 29 HCPs participated in this study. Twenty-four individuals participated in focus groups and 5 individuals completed semistructured interviews. The sample consisted of 22 registered nurses, 1 registered nurse/sonographer, 1 sonographer, and 5 physicians. Participants were mostly female (n = 27, 93.1%) and reported being employed in their health profession between 3 and 32 years (mean = 17.6 years) and in their current area of practice between 1 and 32 years (mean = 14.3 years). Of the 27 participants who were not employed as part of a palliative care consultation team, 17 (58.6%) had interacted with palliative care in some capacity (see Table 1 for further demographic information).

### Thematic synopsis

Communication was the overarching theme, with 3 subthemes that highlighted an aspect of communication: connecting through proximity, protected time and dedicated space, and flexibility and formality. The next section describes these themes with illustrative quotes from participants. Following analysis of the themes, a model of integrated PPC programming is explained along with a description of how each of the 3 sites included in this research study falls along this continuum of program development.

Table 1. **Demographic characteristics of participants (n = 29)**

| Demographic variable | No. | % |
|---|---|---|
| Age, y | | |
| 26-30 | 2 | 6.9 |
| 31-40 | 8 | 27.6 |
| 41-50 | 13 | 44.8 |
| 51-55 | 4 | 13.8 |
| ≥56 | 2 | 6.9 |
| Number of times caring for a fetus or child with a life-limiting or life-threatening illness and their family | | |
| 1-3 times | 1 | 3.4 |
| 4-6 times | 4 | 13.8 |
| 7-10 times | 2 | 6.9 |
| >10 times | 22 | 75.9 |
| In your current area of practice, approximately how many patients/families that you have been involved with have the palliative care team been consulted? | | |
| None | 11 | 34.5 |
| 1-5 patients/families | 12 | 41.4 |
| 6-10 patients/families | 1 | 3.4 |
| >10 patients/families | 2 | 6.9 |
| Not applicable (participant is member of palliative consult team) | 2 | 6.9 |

### Communication

Respondents frequently cited "communication" as the most crucial element in providing PPC. Broadly, communication was seen to facilitate best practice among the specialist teams. However, timely and effective communication with families was seen as vital to the process working well. When communication between teams was weak, the development of a comprehensive care plan was affected, which resulted in unclear goals. The following quote demonstrates how communication impacted processes and role clarification:

> . . . when things go poorly, to me the first thing that goes wrong is communication . . . . Another element that tends to fall apart is confusion about roles of the healthcare team. So we find on some occasions that it's not clear to the family or to the healthcare providers who is attending to what with regards to the baby's needs, and who is primarily responsible and accountable for the needs of the baby and the family. (Sites 2 and 3)

Without a palliative care team in place (at site 1), care planning did not consistently involve the teams outside of the area of obstetrics. Therefore, ensuring information was discussed and then provided to the family directly was crucial, so the plan of care was known and could be relayed to the staff when the mother presented to the hospital in labor.

Sites 2 and 3 identified that as the involvement of a palliative care team increased, so did engagement and communication among the healthcare teams. This resulted in responsibilities being discussed more consistently and roles being negotiated on a consistent basis.

#### *Connecting through proximity*

The physical layout of the various medical buildings restricted or enhanced the ability of teams to connect easily with one another, especially during the labor process and care after the birth of the infant. Physical proximity, therefore, influenced the interdisciplinary approach and level of cohesiveness; as the physical distance between labor units and potential affiliated disciplines increased, the degree of connectedness decreased. At sites 1 and 2, there was significant physical distance between the labor and delivery units and the NICU. Participants reported not feeling as connected to staff in areas related to perinatal care, which limited opportunities to enhance the collegial interactions that could improve high-risk patient care. Conversely, at site 3, all of the labor units and the NICU are situated on the same floor of the hospital, resulting in increased communication among perinatal staff. Their approach seemed to facilitate much closer interactions and a connectedness between staff, allowing neonatology to have more of a presence and take the coordinating role in communicating with teams and providing assistance and support to the labor and delivery units.

### *Protected time and dedicated space*

Participants frequently expressed a desire to have more time to fully enter the caregiving process and engage with families, which included opportunities to spend time with families during the birth and death experience. At site 1, finding a private space as well as spending time with patients was discussed by several participants, with this quote being one example:

> We see a lot of them in fetal assessment. We have much more time there for counselling, to do scans and do all those things .... Because it takes time. It takes an hour every time they come. And we want to be able to give them that time .... We try to keep people's experiences private. We keep them in private rooms away from everybody else with only one nurse if possible. I think it usually goes okay. (Site 1)

All sites discussed ways in which staff tried to make the labor, delivery, and postpartum experience the best that they could for families whose infant had a life-limiting condition. Site 3 highlighted the recent changes they made, encouraging births of infants not expected to survive, to take place in the low-risk area (as long as the mother was not at high-risk for complication) called the labor, delivery, recovery, and postpartum (LDRP) unit. Parents have a private room and all procedures as well as postpartum care occur in the same room, providing staff with the luxury of time in one location with the patient and the family and the private space for the birth experience. The site 3 focus group participants clearly felt that this change had resulted in better overall care:

> We did all the stillbirths or perinatal losses on L & D [Labour and Delivery] .... And we often had a real lack of privacy. When LDRP opened, there were none done on LDRP .... They always came to high-risk. But then we would be sometimes in a room where in the next room you would hear a baby being born and the baby's crying, and this mother knows her baby is not going to cry. It was very hard and it was kind of like, you know what we have LDRP there, the rooms are very private, and they don't really hear anything else. It just makes so much sense. We did perinatal loss workshops with all the staff and it was a bit of a transition for the staff here, but it all of a sudden fell into place. I don't think any of the staff here could argue that it didn't make more sense. (Site 3)

All sites highlighted a variety of ways they tried to improve care and be sensitive to the needs of families, such as providing rooms at the end of the hall to maximize privacy, scheduling appointments at locations where it was quieter, and altering where these women would go to receive their postpartum care, so that there would not be infants in the same room or on the ward.

### *Flexibility and formality*

Several participants described the challenges of teams determining individual roles in the care of perinatal patients, identifying the need for flexibility in the midst of unknown outcomes.

> ... it is not always set out in stone. It can be very complicated at times. I know recently we had a situation where there was a plan that palliative care was involved, but there was confusion as to whether we would call neonatology or the resusc [resuscitation] team. On the plan it said that neonatology and the resuscitation team and respiratory would come to the delivery, but palliative care would be involved also. And the team wasn't exactly sure why they should be present, if the baby would be palliative. So there was kind of like a flip-flop as to who would be caring for this child. So I think sometimes it's not always set in stone what's going to be done. (Site 2)

The focus groups at site 2 recognized the need to develop a group that could evaluate how PPC is provided within their institution. They acknowledged that similar issues arose from their discussion and that identifying issues in the focus group helped them to see the possibilities that could come from simply sitting at the same table. Participants stressed that formalized plans and coordinating the healthcare teams that are involved are necessary. However, they also recognized the need for flexibility to respond appropriately to individual needs:

> What I would like to see is the establishment of a consistent and reliable and formal process for perinatal palliative care so that it's delivered in a similar manner in all care settings so that there is clear identification of roles of individuals who are involved in the care of dying newborns and so there is a standard of care as well for those children's care needs. (Sites 2 and 3)

## A Model for integrated PPC programming

Variations in process, protocol, and experience with PPC programming were evident between the 3 sites. In the focus groups and interviews, factors influencing a site's current state of development and ability to offer PPC programming were frequently described. When evaluating the current literature describing palliative care programming,[3,22,38–41] the differences in aspects of program development in this research study could be captured in 3 evolutionary categories, including (1) emergent, (2) developing, and (3) integrated (see Figure 1).

When a program is created, it is in the emergent stage that is often unstructured, operating with limited financial resources, and depending on specific people instead of having processes in place for provision of consistent care. As a program develops, the emphasis is placed on frameworks and the development of processes, thus focusing more on the needs of the patient population it serves. The elements of an integrated program represent the ideal, wherein PPC is philosophically and programmatically accepted and financially supported, a team concept is applied, training is available, and a collaborative approach among all teams involved in care is utilized. As is evident in Table 2, none of the sites in this study had every element of what has been described in the literature as an ideal and integrated system, all were moving forward on the evolutionary continuum.

Several participants recognized how PPC was provided and that services were changing and being enhanced. They described these changes as a positive process that was improving care for patients and families, as palliative care discussions were now occurring sooner, instead of occurring in the last hours or minutes of life. There was an acknowledgement that in addition to the consultation provided to families, the involvement of the palliative care team impacted the HCPs themselves.

> I also find not only is the palliative care team helpful to the family, but when they are here, they are supporting us. They are making it so much less stressful for us, because they are reassuring us in the things that we are doing and giving us some options and helping us to handle things. It is so much less stressful to do the work that we need to do with them there or with them being even just available to us. (Site 3)

Participants at site 1 were beginning to acknowledge how services could be improved in terms of linkages with community resources and planning for care at home, while recognizing the possibilities as they prepared for the arrival of a pediatric palliative care physician. However, along with these increased resources in palliative care, 1 participant realized that there would come the need to define new roles and work together to provide appropriate care.

> Certainly if we are going to have a team [referring to palliative care team], then that's good and that's bad. It's good because we have someone who is an expert, and can provide excellent services and care for our patients. But it is bad because then we feel that it kind of absolves us of any responsibility for that. And I don't think that's necessarily right. I don't want to just hand this over. I want to be part of a team that does this. (Site 1)

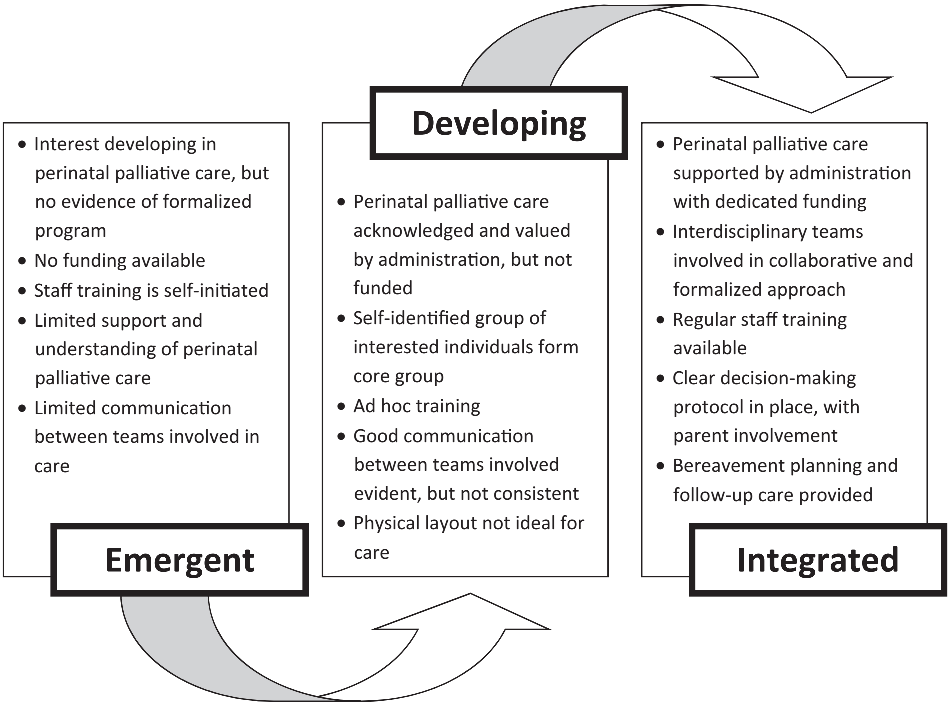

**Figure 1.** A model for integrated perinatal palliative care programming.

Table 2. **Model of integrated palliative care continuum—site comparison**

| Perinatal palliative care variables | Site 1 | Site 2 | Site 3 |
|---|---|---|---|
| A clear understanding of the philosophy of perinatal palliative care | E | D | D |
| Coordinated and standardized perinatal palliative care training available | D | I | I |
| Effective communication evident between healthcare team members | D | D | I |
| Care plan formulated with parents prior to birth | E | D | D |
| Parents provided with the opportunity to take the lead in decision making | E | D | D |
| Healthcare team understands and applies principles of perinatal palliative care | D | I | I |
| Standardized bereavement planning and follow-up care in place | D | D | D |
| Collaborative approach used | D | D | I |
| Palliative care team integrated as one of the specialty teams involved in care | E | D | D |
| Physical layout of wards facilitates delivery of palliative care | D | E | I |
| Key personnel or "champions" identified | D | D | D |
| Clear communication about the plan of care for patients | D | D | I |
| Staff motivated and passionate about providing the best care for patients and families | I | I | I |
| Formal perinatal palliative care programming in place, with stable funding and staff | D | I | I |
| Support and funding for perinatal palliative care available from different levels of stakeholders | E | D | D |
| Unique needs of the perinatal palliative care population recognized | D | D | I |
| An understanding of the roles and responsibilities various teams may have prior to and after the birth | E | D | D |

Abbreviations: D, developing; E, emergent; I, integrated.

Negotiating how care will be provided and who will be involved in each individual case would be one aspect of the communication that needs to occur as program resources are enhanced. This speaks to the need for collaboration among teams and the role that palliative care can play as a consultant in providing support and guidance, enhancing services, without taking over care.

The theme of communication and the subthemes identified in this research study are interwoven in this model of care. Effective communication provides the basis for any program to move forward, identify the needs of the teams involved in providing care, and determine the needs of individual patients while striving to achieve family-centered care. Communication is, therefore, the foundation of this model and the force that assists a program to move toward becoming fully integrated.

## DISCUSSION

This study evaluated the perspectives of HCPs involved with 3 institutions as they developed PPC programs and aimed to become integrated in the services provided. Each of these programs strived to advance, with the themes in this study identifying areas for improvement. The integral theme of communication, along with the subthemes of connecting through proximity, protected time, and dedicated space as well as flexibility and formality, each identifies challenges and opportunities for improvement in the delivery of PPC. Some of these challenges, specifically the concerns about adequate space and proximity of healthcare teams, are larger administrative issues that require physical location changes. It is interesting to note that at sites 1 and 2, where physical space and proximity were identified as considerable issues, building projects for their women's health programs were in development or underway. To address issues that pertained to all 3 sites, and are realistic to implement in any PPC program, this discussion will focus specifically on the themes of communication as well as flexibility and formality, as they relate to the model of integrated programming.

All of the sites in the study recognized the lack of communication between teams and the resulting inconsistencies in providing PPC. They spoke of the need to develop more reliable and formalized processes and put structures in place (similar to a care pathway) to ensure that appropriate providers are involved with patients and families during this experience. The organization of standardized processes requires that various teams work together to develop practices that function for their facility and the families they serve. This process alone could begin to improve communication among HCPs. An integral part of a standardized process would include developing a care plan template for families to complete with HCPs to assist in identifying goals of care. This would enhance communication among HCPs and the family, assist the family in being a part of planning and continued decision making, and provide flexibility and formality that is desired by the 3 programs and suggested as a critical component of care provision and moving along the continuum of the model of integrated program development.

Communication has been identified as a barrier within the pediatric palliative care literature, specifically in how HCPs interact with families. Attitudes related to palliative care for infants with life-limiting conditions are changing; an increasing number of parents are more open to a palliative care philosophy and want to be more involved with their dying infant.[42] Good communication is central to an effective and efficient caregiving process. It enhances the ability to create and implement a cohesive plan with the family. When lacking, it can lead to difficulties navigating the patient and the family through the various specialty teams. Parents who have experienced the death of an infant underscore the importance of being an integral part of communication by becoming the central decision makers in their child's care.[43,44] They valued empathic support, kindness, professional expertise, sensitivity, and language that acknowledged their infant; staff who both listened and kept them informed; as well as staff who affirmed the status they have as parents and the value of their infants and respected the parents' choices.[43–46] Parents appreciate being offered informed choices and being guided but not directed or controlled in decision making.[44] Parents identify areas that were problematic with the healthcare environment such as communication between HCPs, feeling abandoned or avoided, insensitive treatment, fragmented healthcare, and a lack of coordinated bereavement follow-up.[17,47,48] Infants and families may benefit the most from coordinated interdisciplinary care, with parents maintaining the role as primary caregivers and decision makers.[49] Thus, it is imperative that care is consistently focused on the needs of the family and the patient. With respect to PPC, this could begin during the prenatal period and extend to the provision of adequate bereavement support and follow-up. The desires of the HCPs in this study were to enhance communication with families and be able to continually improve the services the teams provide.

The model for integrated PPC described in this study enhances the recent analysis of the literature by Balaguer and colleagues.[14] that describes a conceptual evolution of PPC that includes the physical aspects of care, psychosocial components, and the perspective of when care should be initiated. The findings from this study augment this information by providing specific indicators of what is crucial in the development of programs from the perspective of HCPs.

## STUDY LIMITATIONS

Study participants were HCPs situated in 2 provinces in Canada and reflected a cross section of professionals involved in the delivery of perinatal care. The vast majority of the sample was nurses and females, which is an adequate representation of the overall staff ratio and demographic within this area of healthcare. Participants may have selected to participate in this study because they are comfortable with the topic of palliative care and have a personal interest in the area relative to other HCPs who did not participate. The sample size was small, and participants were not observed in their practice and thus the research conclusions are based solely on the perceptions shared during the focus groups or interviews. Interviews were short and typically conducted over the phone, which may have affected communication by obscuring nonverbal cues. Despite these limitations, the transferability of the themes and model developed from this research can be useful for a variety of settings where PPC is provided.

## RECOMMENDATIONS

All of the participants acknowledged that the perinatal programming provided at their places of employment could be improved and that there were specific implications for how they practiced. Several participants identified barriers that affected care. Site 1 faced the challenge of moving forward with the implementation of a new pediatric palliative care service within its organization. This involved incorporating a program within existing structures and systems, which were open to change. The goal this site was working toward included enhanced linkages with resources throughout the province, particularly neonatal hospital resources and community adult-based palliative care programs. To gain a better understanding of the services they desire to provide, all 3 sites may want to consider undertaking an environmental scan. This suggestion is provided in the literature as the first step in determining

Table 3. **Bereavement resources**

| Bereavement resource | Web site |
|---|---|
| The Compassionate Friends | http://www.compassionatefriends.org |
| Resolve Through Sharing | http://www.bereavementservices.org/resolve-through-sharing |

the population served, as well as the desires and needs of various stakeholders.[39,50–52] Moving forward with an environmental scan would require further communication and clarification of roles among teams. It would involve the participation of HCPs and families as a crucial part of the evaluation, development, and coordination of comprehensive care. This would address what was identified in this study as a lack of cohesiveness for all teams involved in PPC.

To implement new initiatives and continue to develop programs, education of staff is a vital piece to enhance communication and develop an understanding of the philosophy of PPC and highlight how it is being implemented in the specific institution. It is clear that palliative care education for HCPs remains woefully inadequate,[53–55] and insufficient knowledge of palliative care is a barrier within the pediatric system.[56] Inadequate education can lead to misconceptions regarding the goals and philosophy of palliative care and thus impact the communication that HCPs have with each other and with families. Standardized education has been suggested as a key component of integrated care[39] and an aspect of program development that all 3 sites could utilize to work toward more formalized and integrated programming.

All sites could consider evaluating other programs currently in existence[10,13,21,57,58] to determine whether aspects of these programs are feasible to implement where they provide care. Utilizing bereavement resources already in existence and developing partnerships with organizations could enhance PPC education and resources available to families (see Table 3).

To promote the development of integrated PPC programming, it is necessary to take pragmatic steps to enhance HCP communication, improve feedback and evaluation, expand education, as well as incorporate families into the care planning process.

In summary, there is mounting evidence that PPC requires formal, integrated programming and that further research is required to evaluate the overall experience of patients and families accessing PPC services. It would be useful to describe how previous experience and exposure to PPC influences individual HCPs' perspectives. Research evaluating the assessment and management of symptoms in infants at the end-of-life is desperately required. Studies that focus on the experiences and perspectives of families choosing to carry the pregnancy to term when a life-limiting condition is diagnosed would be of value. In particular, longitudinal studies to explore the impact of PPC services on the experiences of families over time would be helpful in this burgeoning area of healthcare.

## References

1. Sumner LH, Kavanaugh K, Moro T. Extending palliative care into pregnancy and the immediate newborn period. *J Perinat Neonatal Nurs.* 2006;20(1):113–116.
2. Field MJ, Behrman RR, eds. *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*. Washington, DC: Institute of Medicine of the National Academies; 2003.
3. British Association of Perinatal Medicine. *Palliative Care (Supportive and End-of-Life Care): A Framework for Clinical Practice in Perinatal Medicine: Report of the Working Group*. London, UK: British Association of Perinatal Medicine; 2010.
4. Hoeldtke N, Calhoun BR. Perinatal hospice. *Am J Obstet Gynecol.* 2001;185(3):525–529.
5. Leuthner SR. Palliative care of the infant with lethal anomalies. *Pediatr Clin North Am.* 2004;51(3):747–759.
6. Munson D, Luethner SR. Palliative care for the family carrying a fetus with a life-limiting diagnosis. *Pediatr Clin North Am.* 2007;54:787–798.
7. World Health Organization. WHO definition of palliative care [Internet]. http://www.who.int/cancer/palliative/definition/en. Accessed July 1, 2013.
8. Kramer R, Sehring S, Ratto T, Hopkins LM. Addressing perinatal palliative care program development. *J Pain Symptom Manage.* 2010;39(2):371–372.
9. de Rooy L, Aladangady N, Aidoo E. Palliative care for the newborn in the United Kingdom. *Early Hum Dev.* 2012; 88(2):73–77.
10. Ramer-Chrastek J, Thygeson MV. A perinatal hospice for an unborn child with a life-limiting condition. *Int J Palliat Nurs.* 2005;11(6):274–276.
11. American College of Obstetricians and Gynecologists, Committee on Ethics & American Academy of Pediatrics, Committee on Bioethics. Clinical report: maternal-fetal intervention and fetal care centers. *Pediatrics.* 2011;126(2):e473–e478.
12. Calhoun BC, Napolitano P, Terry M, Bussey C, Hoeldtke NJ. Comprehensive care for the family of the fetus with a lethal condition. *J Reprod Med.* 2003;48(5):343–348.
13. D'Almeida M, Hume RF, Lathrop A, Njoku A, Calhoun BC. Perinatal hospice: family-centred care of the fetus with a lethal anomaly. *J Am Phys Surg.* 2006;11(2):52–55.
14. Balaguer A, Martin-Ancel A, Ortigoza-Escobar D, Escribano J, Argemi J. The model of palliative care in the perinatal setting: a review of the literature. *BMC Paediatr.* 2012;12(25):25.
15. Breeze AC, Lees CC, Kumar A, Missfelder-Lobos HH, Murdoch EM. Palliative care for prenatally diagnosed lethal fetal abnormality. *Arch Dis Child Fetal Neonatal Ed.* 2007;92(1): F56–F58.
16. Leuthner S, Jones EL. Fetal concerns program: a model for perinatal palliative care. *Am J Maternal /Child Nurs.* 2007; 32(5):272–278.
17. Côté -Arsenault D, Denney-Koelsch E. "My baby is a person": parents' experiences with life-threatening fetal diagnosis. *J Palliat Med.* 2011;14(12):1302–1308.
18. Redlinger-Grosse K, Bernhardt BA, Berg K, Muenke M, Biesecker BB. The decision to continue: the experiences and needs of parent who receive a prenatal diagnosis of holoprosencephaly. *Am J Med Genet.* 2002;112(4):369–378.
19. Widger K, Davies D, Druoin D, et al. Pediatric patients receiving palliative care in Canada: results of a multicenter review. *Arch Ped Adolesc Med.* 2007;161(6):597–602.
20. Youngblut JM, Brooten D. Perinatal and pediatric issues in palliative and end-of-life care from the 2011 Summit on the Science of Compassion. *Nurs Outlook.* 2012;60(6):343–350.

21. Leong Marc-Aurele K, Nelesen R. A five-year review of referrals for perinatal palliative care. *J Palliat Med.* 2013;16(10):1232–1236.
22. Catlin A, Carter B. Creation of a neonatal end-of-life palliative care protocol. *J Perinatol.* 2002;22(3):184–195.
23. Jassal SS. *Basic Symptom Control in Paediatric Palliative Care: The Rainbows Children's Hospice Guidelines*. 9th ed. Bristol, England: Together for Short Lives; 2013.
24. Janvier A, Meadow W, Leuthner SR, et al. Whom are we comforting? An analysis of comfort medication delivered to dying neonates. *J Pediatr.* 2011;159(2):206–210.
25. Van Der Wolde J, Engels B, Zeeman G, Bos AF, Verhagen AAE. Palliative care medication in dying newborns in the delivery room. *Arch Dis Child.* 2008;93:espnic17.
26. Harlos MS, Stenekes S, Lambert D, Hohl C, Chochinov HM. Intranasal fentanyl in the palliative care of newborns and infants. *J Pain Symptom Manage.* 2013;46(2):266–274.
27. Carter BS, Jones PM. Evidence-based comfort care for neonates towards the end-of-life. *Semin Fetal Neonatal Med.* 2013;18(2):88–92.
28. Carter BS, Levetown M. *Palliative Care for Infants, Children and Adolescents*. Baltimore, MD: John Hopkins University Press; 2004:44–68.
29. Kain VJ. Palliative care delivery in the NICU: what barriers do nurses face? *Neonatal Netw.* 2006;25(6):387–392.
30. Wright V, Prasun MA, Hilgenberg C. Why is end-of-life care delivery so sporadic? A quantitative look at the barriers to and facilitators of providing end-of-life care in the neonatal intensive care unit. *Adv Neonatal Care.* 2011;11(1):29–36.
31. Wool C, Northam S. The perinatal palliative care perceptions and barriers scale instrument. *Adv Neonatal Care.* 2011;11(6):397–403.
32. Wool C. Clinician confidence and comfort in providing perinatal palliative care. *J Obstet Gynecol Neonatal Nurs.* 2013;42:48–58.
33. Wool C. State of the science on perinatal palliative care. *J Obstet Gynecol Neonatal Nurs.* 2013;42:372–382.
34. Wool C. Systematic review of the literature: parental outcomes after diagnosis of fetal anomaly. *Adv Neonatal Care.* 2011;11(3):182–192.
35. Shapiro MF, Berk ML, Berry SH, et al. National probability samples in studies of low-prevalence diseases. Part I: perspectives and lessons from the HIV cost and services utilization study. *Health Serv Res.* 1999;34(5, pt 1):951–968.
36. Schutt RK. *Investigating the Social World: The Process and Practice of Research*. 6th ed. California, CA: Pine Forge Press (Sage); 2009.
37. Shank GD. *Qualitative Research: A Personal Skills Approach*. Columbus, OH: Prentice Hall; 2002.
38. American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care. Palliative care for children. *Pediatrics.* 2000;106(2, pt 1):351–357.
39. Association for Children's Palliative Care. *A Neonatal Pathway for Babies With Palliative Care Needs*. Bristol, England: Association for Children's Palliative Care; 2009.
40. Carter BS. Providing palliative care for newborns. *Pediatr Ann.* 2004;33(11):770–777.
41. National Association of Neonatal Nurses. Palliative care for newborns and infants: position statement #3051. www.nann.org/uploads/files/Palliative_Care-final2-in_new_template_01-07-11.pdf. Accessed July 1, 2013.
42. Bhatia J. Palliative care in the fetus and newborn. *J Perinatol.* 2006;26(suppl 1):S24–S26.
43. Einaudi MA, Le Coz P, Malzac P, Michel F, D'Ercole C, Gire C. Parental experience following perinatal death: exploring the issues to make progress. *Eur J Obstet Gynecol Reprod Biol.* 2010;151(2):143–148.
44. Henley A, Schott J. The death of a baby before, during or shortly after birth: good practice from the parents' perspective. *Semin Fetal Neonatal Med.* 2008;13(5):325–328.
45. Lathrop A, VandeVusse L. Affirming motherhood: validation and invalidation in women's perinatal hospice narratives. *Birth.* 2011;38(3):256–265.
46. Widger KA, Wilkins K. What are the key components of quality perinatal and pediatric end-of-life care? A literature review. *J Palliat Care.* 2004;20(2):105–112.
47. Chitty LS, Barnes CA, Berry C. Continuing with pregnancy after a diagnosis of lethal abnormality: experience of five couples and recommendations for management. *BMJ.* 1996;313(7055):478–480.
48. Widger K, Picot C. Parents' perceptions of the quality of pediatric and perinatal end-of-life care. *Pediatr Nurs.* 2008;34(1):53–58.
49. Hynson JL, Sawyer SM. Paediatric palliative care: distinctive needs and emerging issues. *J Paediatr Child Health.* 2001;37(4):323–325.
50. Kobler K, Limbo R. Making a case: creating a perinatal palliative care service using a perinatal bereavement program model. *J Perinat Neonatal Nurs.* 2011;25(1):32–41.
51. Liben S, Papadatou D, Wolfe J. Pediatric palliative care: challenges and emerging ideas. *Lancet.* 2008;371(9615):852–864.
52. Price J, McNeilly P. Developing an educational programme in paediatric palliative care. *Int J Palliat Nurs.* 2006;12(11):536–541.
53. Bomba P. Enabling the transition to hospice through effective palliative care. *Case Manager.* 2005;16(1):48–52.
54. Sanders BS, Burkett TL, Dickinson GE, Tournier RE. Hospice referral decisions: the role of physicians. *Am J Hosp Palliat Care.* 2004;21(3):196–202.
55. Taylor CL. Improving referral of patients to hospice through community physician outreach. *J Pain Symptom Manage.* 2004;28(3):294–295.
56. Davies B, Sehring SA, Partridge JC, et al. Barriers to palliative care for children: perceptions of pediatric health care providers. *Pediatrics.* 2008;121(2):282–288.
57. Gale G, Brooks A. Implementing a palliative care program in a newborn intensive care unit. *Adv Neonatal Care.* 2006;6(1):37–53.
58. Engelder S, Davies K, Zeiliner T, Rutledge D. A model program for perinatal palliative services. *Adv Neonatal Care.* 2012;12(1):28–36.

The CE test for this article is available online only. Log onto the journal website, www.JPNONline.com, or to www.NursingCenter.com/CE/JPN to access the test. For more than 76 additional continuing education articles related to perinatal nursing, go to NursingCenter.com\CE.