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Nursing considerations and interdisciplinary coordination in the care of conjoined twins

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ABSTRACT

Traditional nursing care strategies may require modification to meet the unique needs of conjoined twins. Here we discuss the strategies found to be useful in planning for and responding to distinctive circumstances encountered throughout hospitalization, as well as lessons learned. Areas of focus include ensuring privacy, designing adequate unit accommodations to meet space and equipment needs, staffing considerations and adaptations to typical neonatal intensive care nursing interventions. The utility of a team-based approach to interdisciplinary care coordination is also discussed. With adequate preparation and thoughtful innovation, most tertiary neonatal intensive care units can readily adapt to the unique needs of conjoined twins.

Introduction

Care of conjoined twins is a complex process and the role of the nurse is an important influencer of the overall outcome. Even the most routine nursing tasks must be amended to accommodate these unique patients' needs. Lessons learned in caring for three sets of conjoined twins will be presented here, with discussion of specific strategies to optimize care. The goal is to provide potential approaches for a unit that is planning to care for conjoined twins.

Unit accommodations for conjoined twins

When a Neonatal Intensive Care Unit (NICU) is expecting an admission of conjoined twins, care must be taken to ensure adequate preparation of space and equipment. Factors to

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consider when preparing for admission include space, privacy, layout and patient identification.

Space planning

The amount of medical and nursing care equipment anticipated for conjoined twins is at least double that of what is needed to care for a single neonate. Fig. 1 demonstrates a bed space layout for thoraco-omphalo-ischiopagus conjoined twins born at 31 weeks' gestation who needed respiratory support after delivery. Equipment must be placed around the bed in a way that clearly delineates association with each twin. Space is also needed for providers to access babies from both sides in order to provide routine care and assessment. As the twins grow and convalesce clinically, it is important to recognize the likelihood of intermittent procedures that could require the temporary return of more intensive medical equipment. The need for a specialty bed must also be considered. In two sets of twins that progressed to separation, a Clinitron® Rite Hite® Air Fluidized Therapy Bed (Hill-Rom, Chicago, IL) was essential in preventing skin breakdown during skin expansion. A Clinitron® bed is an air fluidized therapy bed that is typically used in adult patients. Though valuable in remedying pressure points, it requires much more space than a typical NICU bed. Emergency situations should also be taken into consideration when choosing a bed space, as the space must accommodate the equipment and personnel needed to resuscitate both infants simultaneously. Visibility of monitors is necessary for both regular monitoring of vital signs as well as adequate visualization in an emergency. Additionally, as the twins grow they will require equipment at the bedside to assist in positioning and developmental therapies.

Privacy

Privacy is a primary concern for conjoined twins and their families. Private rooms are ideal as they allow the most privacy but may not be large enough to accommodate necessary equipment and may present spatial challenges in emergency situations. Utilizing open pod bed spaces can provide space at the cost of decreased privacy.

At our facility, two bed spaces in a corner location of an open pod were combined into a single area that could accommodate the large amount of equipment each twin needed throughout their NICU course (Figure 2b). This arrangement allowed each twin to have their own monitor assigned at a separate bed space, which enabled digital recording of vital signs for each infant with direct input into the electronic medical record (EMR). Portable privacy screens did not provide enough contiguous height or width to ensure privacy in such a large area, so facilities operations installed retractable curtains around the two bed spaces. Curtains were hung from the ceiling to just above the floor on a track, in order to provide privacy while allowing ample access in an emergency.

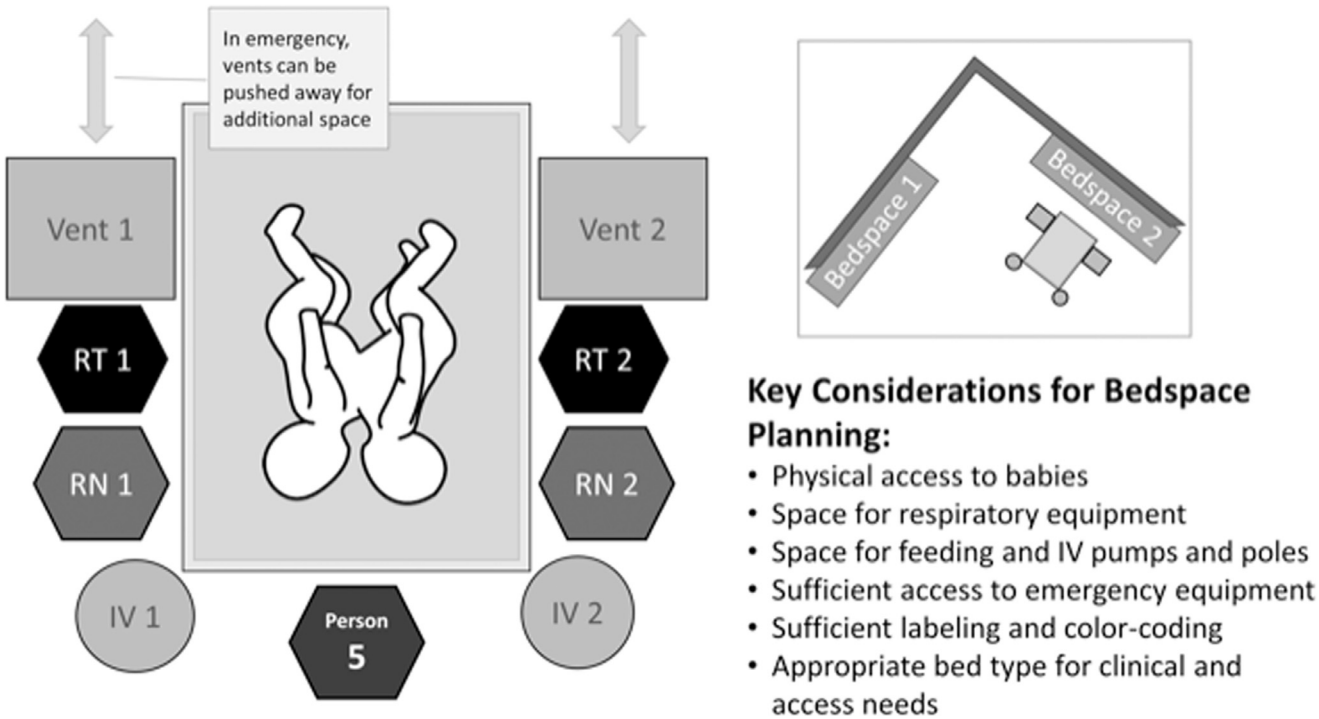


Fig. 1 – Bedspace layout for conjoined twins after birth. Use of adjacent bed spaces in an open bay NICU provided adequate space for conjoined twins and the equipment needs. This configuration allows for access to the twins by two respiratory therapists (RT 1 and 2), two bedside nurses (RN 1 and 2) and a fifth person to assist from the head of the bed. Ventilators (vent 1 and 2) are at the foot of the bed and can be pushed away for additional access to the twins if needed. Intravenous poles (IV 1 and 2) are at the head of the bed. Considerations for space planning are listed. Care providers must consider the potential for evolving equipment needs to accompany changes in patient size, developmental level and clinical status.

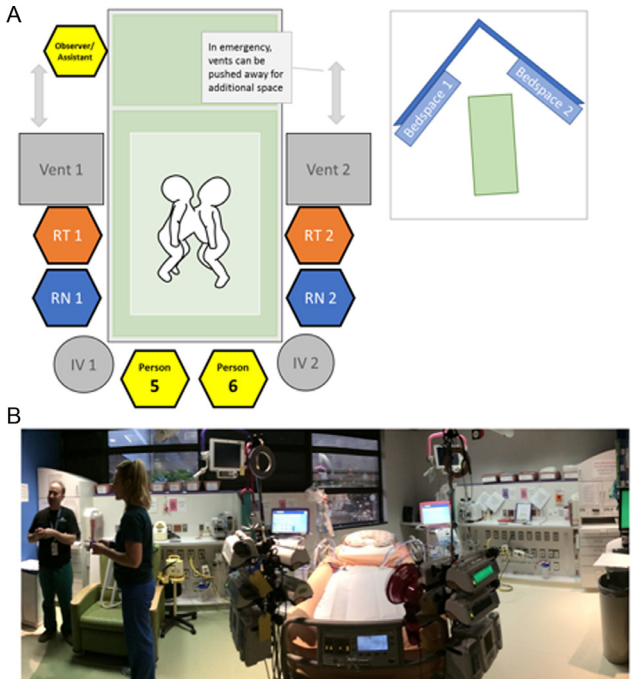


Fig. 2 – Bedspace layout for intubated conjoined twins with Clinitron® bed. (A) Bedspace layout for conjoined twins with a large specialty bed positioned at an angle to the head wall, as opposed to the perpendicular position used with a standard-sized NICU crib. Ventilators (vent 1 and vent 2) are positioned so ventilator tubing can reach each twin but each ventilator can be pushed away to allow more room at bedside in case of emergency. IV poles (IV1 and IV2) are near the foot of the bed. This configuration allows for two nurses (RN) and two respiratory therapists (RT) at both sides of the bed, and an additional person for each twin at the head of the bed (Person 5 and 6). An additional observer position was identified near the head of the bed to assist in coordination and additional observations during an emergency event. (B) A wide-angle view of the bed space shows the orientation of the Clinitron® bed relative to the head walls. The color-coding of equipment can also be seen here, in addition to the color identification signage and just-in-time training tools and binder (on head wall at right). Retractable privacy curtains (not shown) surround this area to provide privacy while allowing for ample access in an emergency.

Layout

The bed should be positioned to allow access to both patients, their supplies and equipment. With a warmer or crib, it is possible to position the head of bed (HOB) flush against the head wall. However, with a large bed like the Clinitron®, it was necessary to angle the HOB away from the head wall to accommodate space and equipment needs. The positions of our conjoined twins' heads alternated from HOB to the foot of the bed every 2-4 h to relieve constant pressure on their sides. This required additional room around the bed to accommodate an atypical method of repositioning while preventing tangled lines and tubing. Additional details are discussed in the Positioning section.

It is necessary to have proper storage for personal belongings and medical supplies during a lengthy hospitalization. Storing supplies in a consistent manner ensures efficient access and decreases waste. The bed space should be deeply cleaned at regular intervals. Environmental cleaning and disinfection is essential to reducing healthcare associated infections[1]. Thorough cleaning can be achieved when the twins go to a procedure or at other scheduled times. If the patients are unable to tolerate the movement needed for a deep clean of the bed space, then the cleaning should be thoughtfully rescheduled. Keeping a record of the last cleaning and next scheduled cleaning helps ensure cleanliness of the area throughout hospitalization.

Patient identification and color coding

One of the most important aspects of caring for conjoined twins is having an efficient and reliable system for identifying each baby. Through simulations, procedures and emergency situations, we found that using color designations was the most effective method for correct identification, communication and shared mental modeling during the care of conjoined twins. Although using identifications of 'Twin A' and 'Twin B' or using their given names can delineate the twins, color identification provided the opportunity for visual cues that corresponded to patient identification and created a seamless association with verbal communication. All equipment and monitors were clearly and extensively labeled with their respective color and corresponded to the color identification and labeling of each twin. Medications during procedures and emergencies were labeled with colored tape to ensure that the correct twin received the medication. During procedures and emergency situations, team members were assigned and often labeled with one of two colors to delineate which twin they were assisting. This system allowed team members to quickly communicate patient status with precise understanding of the affected twin, enabled accurate interventions and adjustments to be made to the correct equipment, and helped efficiently delineate roles throughout procedures or emergencies. For example, during a respiratory decompensation verbal communication might include, "Pink oxygen saturation at 60%. Pink respiratory therapist, provide bag-mask ventilation." We found this to be critical throughout the entire hospitalization through separation. Frequent reminders to utilize color-based identification were beneficial, as twins are typically identified in the NICU by the conventional "Twin A" and "Twin B".

Assigning color identification prior to birth allowed color-based communication in the delivery room. This enabled our team to relate prenatal imaging to the twins immediately after birth. These colors were then used consistently throughout their hospitalization until following separation. We found green and pink to be sufficiently different to eliminate confusion while being visually acceptable to the family of female conjoined twins. This decision was also influenced by ready availability of pink and green self-adhesive tape that could be used for equipment labeling. More similar colors, such as pink and purple, were not sufficiently distinguishable.

Table 1 – Bedside items that should be clearly labeled according to established color code. The goal of color coding patients, equipment and personnel is to reduce confusion, medical errors and the potential for delays in care in an emergency. This list, though not exhaustive, outlines many of the items that should be considered for color coding at the bedside.

- **Bed rails alongside each twin**
- **IV Equipment:**
  - IV poles
  - IV pumps
- **Feeding equipment:**
  - Feeding pumps
  - Feeding tubes
- **Monitoring equipment:**
  - Vital sign monitors
  - Pulse oximeter cable
  - Blood pressure cuff
  - Cardiac leads
- **Respiratory equipment:**
  - Respiratory support device (eg. Ventilator, CPAP setup, HFNV setup)
  - Respiratory tubing
  - Emergency respiratory equipment (eg. Respiratory bags, advanced airway options)
  - Suction setups and tubing
- **Medication drawers**
- **Storage compartments**

Table 1 lists items to include when implementing a color-coded identification system. Signage at the bedside should be clear and easy to read, with 'A' and 'B' on separate signs with their colors displayed prominently (Figure 2b). This allows anyone approaching the bedside to identify each twin, their supplies and equipment. Other signage and decorations should be kept at a minimum to keep the color coding clear.

Staffing considerations with conjoined twins

Primary nursing

Primary nursing improves the quality of nursing care in complex patients[2]. It allows for patient-centered care, expert bedside care providers, continuity of care, consistent communication, and development of trust and comfort between staff and families[3,4].

Using primary nurses to care for complex patients provides valuable insight to the medical team such as identification of clinical patterns, recognition of subtle changes, and more meaningful understanding of observed behaviors. For example, a primary nurse noted when one twin received sedation through an extremity that the other twin would become sedated. This led to an increased understanding of cross circulation that was important for future medical procedures and useful in devising protocols for medication administration during emergency situations.

Primary nurses are typically established during the postnatal period. However, with conjoined twins, it is important for the nurses taking care of the twins immediately following delivery to have an understanding of their anatomy and expected physiology and to be prepared for emergencies by participating in simulations specific to the individual set of twins. For these reasons, conjoined twins benefit from a primary nursing team that is established prenatally.

Caring for conjoined twins requires commitment to a long-term assignment, as conjoined twins may require prolonged hospitalization. Other responsibilities such as precepting should be taken into consideration before accepting a primary nurse role in conjoined twins. Taking care of conjoined twins can require heavy lifting, especially as the patients continue to grow and strive to meet developmental milestones. Primary nurses should be able to meet increased physical demands.

Primary nurses should be passionate about their assignment and interested in a role requiring increased autonomy and leadership. Nurses may be called on around procedures and meetings to clearly and effectively communicate bedside findings and articulate the multidimensional needs of the patients. Nurses should also be aware of the potential for publicity and media involvement around conjoined twins.

Our NICU also engaged a team of 'backup' nurses that had an understanding of the twins' anatomy and physiology and could step in to provide seamless bedside care if primary nurses were unavailable. A binder was created for this team that included information such as an overview of anatomy and diagnoses, contact information for primary clinical team members and emergency responders, daily care routines, guidance on optimal positioning with pictures and diagrams for playtime, and instructions and diagrams for code or emergency situations. Although these 'backup' nurses were familiar with their assigned patients, this binder helped provide important real-time information to maintain a consistently high level of attention to the nuances of caring for conjoined twins.

Having a child hospitalized with complex medical problems causes significant stress on a family[5]. The consistency of primary nurses provides an opportunity to observe family dynamics. This helps the care team optimize communication, manage parent education, and understand coping mechanisms. The primary nurse often becomes a strong, supportive patient and family advocate and is able to identify and seek out beneficial resources.

Staff preparation

When a NICU anticipates delivery of conjoined twins, proactive education, simulation and training should take place and involve the primary nursing team. The rarity of this condition begets the need to review basic concepts in anatomy and physiology in order to understand the impact of connected structures on overall function. Preparation with the entire medical team is useful in reviewing what is known about the twins and anticipating the impact on patient care. This includes recognition of potential issues with standard nursing care strategies and adjustments needed for successful implementation. This also includes developing protocols for emergency situations that are specific to each set of conjoined twins, utilizing simulation to test and optimize procedures. A full discussion is provided in a separate manuscript on the utility of simulation with conjoined twins. Important topics include:

- Team members required for a code.
- Team member position and role delineation.
- Adjustments required to normal resuscitative algorithms due to the conjoined anatomy, including:
  - Recommendations for airway and intravenous access given their anatomy.
  - Considerations in medication administration such as dosing and route of administration.
  - Guidance on necessary monitoring.

The prenatal plan also includes developing daily safety checks to ensure that established emergency procedures could be followed if needed. These daily checks consisted of:

- Assuring all bedside equipment needed for each patient was available in the event of a code. This included:
  - Individual color-coded stethoscopes.
  - Resuscitation bags and masks.
  - Alternative airways in appropriate sizes located on designated sides of the bed.
  - Suction and oxygen administration equipment with extension tubing long enough to reach each patient.
- Consistent positioning of patients on the designated side of the bed with appropriate color identification of the bed space and equipment (e.g., green twin and equipment always on left, pink twin and equipment always on right).
- Laminated code plans available at bedside including diagram of code team members and roles (Figure 3).

Multidisciplinary meetings throughout hospitalization incorporate all clinical observations and promote a universal understanding of the twins' anatomy and physiology. Visualizing and discussing diagnostic studies such as prenatal scans, MRI, ultrasound, and CT scans provide an understanding of underlying anatomy to enhance the meaning of clinical observations at bedside.

Nurse staffing

Providing safe staffing for conjoined twins is an important component of managing their care. A staffing plan should be initiated well in advance of the conjoined twins' admission to the NICU. We recommend two to three primary nurses be assigned on both day and night shift. The nurse manager should discuss with the nurses individually the level of complexity required to serve as a primary nurse. If they do not wish to partake in the primary role, then disengagement must occur to allow for adjustments to the plan and seeking of alternative primary nurses.

The conjoined twin assignment should be regarded with fluidity in meeting patient needs. Changes in condition may require additional staffing assistance or a change of the standard nurse to patient ratio. An increase in nursing care hours is also usually required with changes in acuity or on the day of a procedure. When necessary, primary nurses for the twins in our NICU would switch shifts, pick up approved overtime, and work with each other's schedules to make sure they were able to work any day there was a procedure. Any staffing changes should be discussed frequently with the primary nurses, ensuring close collaboration.

Nurse managers may find it challenging to safely staff for all the patients in the NICU during the time conjoined twins are hospitalized. Temporary increases in staffing for conjoined twins must be considered and accomplished carefully as to not detract resources from other high acuity patients. The nurse manager should clearly and consistently communicate the need for additional staffing resources to upper level clinical supervisors, especially in advance of any surgery or procedure.

Nursing care considerations

Privacy

Protecting patient privacy begins with understanding hospital privacy standards, Health Insurance Portability and Accountability Act (HIPAA) regulations, and state board of nursing mandates. Rules for protecting patient privacy should be frequently discussed during nursing hand-offs and amongst care providers, charge nurses and leadership. Access to protected health information (PHI) can be controlled through technological barriers in the EMR such as "break the glass" functionality (Epic Systems Corporation, Verona, WI), and through hospital personnel by prohibiting patient discussions in public spaces such as elevators, hallways and break rooms. Information sharing in meetings should be conducted on a need-to-know basis. Discussion of patient care information on social media, including photo sharing, may constitute sharing of PHI and violate HIPAA[6].

It is important for nursing and medical leaders to empower and encourage primary nurses to protect patient information at the bedside. Primary nurses quickly become familiar with primary providers and must be confident in asking for identification and the reason for a visit from an unfamiliar or unexpected person. In the event of a perceived or actual privacy breech, primary nurses must escalate issues through the proper chain(s) of command. Families of conjoined twins may or may not wish to share information about their babies publicly and the hospital should work closely with the family to align with their personal wishes. Primary nurses must be prepared for Public Relations and media involvement. Questions and concerns around privacy should be addressed through professional hospital resources.

Positioning

The primary goals in determining optimal positions for conjoined twins are to be developmentally appropriate, allow for comfortable rest, and minimize pressure on the skin. Anatomical limitations evolve as the patients grow and optimal positioning must be constantly readdressed. Innovative use of positioning aids is the mainstay of meeting complex positioning needs.

In our experience caring for thoraco-omphalopagus conjoined twins, the primary challenge was to determine optimal positioning of the upper extremities, head and neck. The babies' arms were initially crossed behind the opposite twin's neck (Figure 4a), which ultimately produced too much weight on the arm laying under the opposite twin as they grew in size. We then began to place their arms down by their sides in

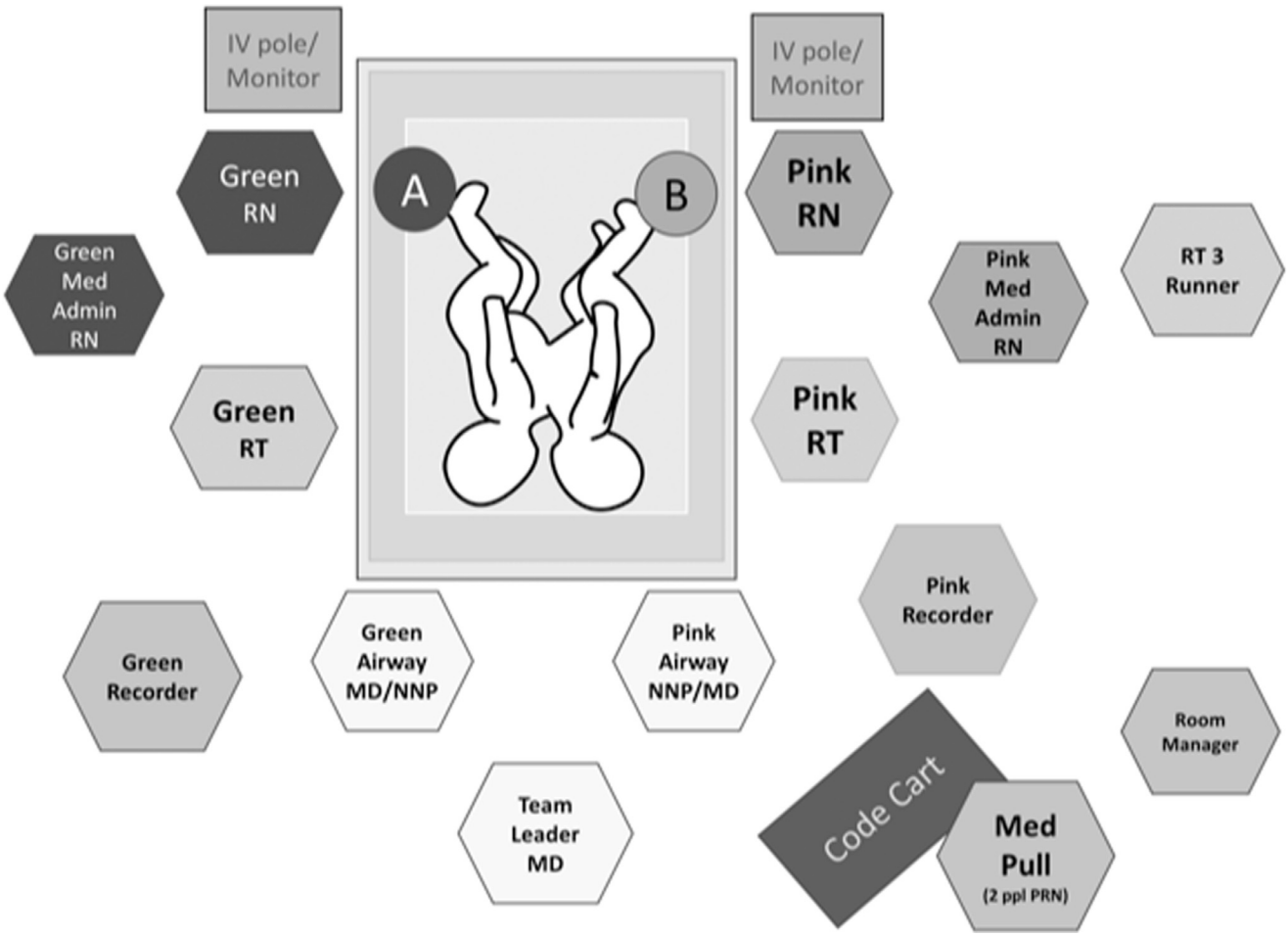


Fig. 3 – Emergency response personnel layout. Emergency planning is beneficial due to extensive personnel and equipment requirements for resuscitation. A proactive approach ensures a collective understanding of the roles and responsibilities of emergency response team members. This figure illustrates the role and location of each code attendant as well as the equipment crucial to a code. This plan was developed through multiple rounds of bedside simulation. Note the providers assigned to each twin are listed by color. The presence of a Room Manager is intended to ensure all necessary personnel are present while also conducting crowd control and ensuring removal of any non-essential personnel in order to minimize unnecessary noise and movement in the patient care area. This diagram was distributed to the entire clinical team. It was also printed and kept at bedside.

between where they were conjoined (Figure 4b). However, this space disappeared after skin expander insertion, again requiring the need to cross their arms behind the opposite twin's neck (Figure 4c). To relieve the pressure on the arm and the skin expander, we used an air-fluidized adult-sized bed (Clinitron®) for continuous pressure redistribution.

Head and neck positioning was also a prominent concern. In two sets of thoraco-omphalopagus twins, the babies' faces were constantly positioned closely to one another. This led the twins to extend their necks away from each other, leading to hyperextension and occasional desaturations. Z-flo™ fluidized positioners (Mölnlycke Health Care, Norcross, Georgia) were placed behind their heads to prevent excessive hyperextension without added pressure on the skin. Gel pillows (DandleLION™ Medical, Danbury, CT) were used under their heads to relieve pressure from their shoulders.

We had significant success with holding the twins. Although initially intimidating to achieve, being held by family members allowed the twins to be upright with extremities supported without creating pressure points. The infants and families enjoyed time spent holding and this generally resulted in improved respiratory status.

Physical therapists collaborated with orthotists to create specialized devices such as a tummy time table and a conjoined twin swing (Figure 5). It was important for primary nurses to become experts in using these specialized positioning devices in order to facilitate just-in-time training of other care providers. The twins were placed in either the swing or the tummy time table once per shift as tolerated until the devices were outgrown. Although these custom specialty devices provided some beneficial positioning options, we found utilizing readily-available positioning devices in creative ways to be easier and more efficient for the clinical staff.

Maintaining skin integrity

Maintaining the skin integrity of conjoined twins can be challenging due to limited positioning and mobility. We utilized a

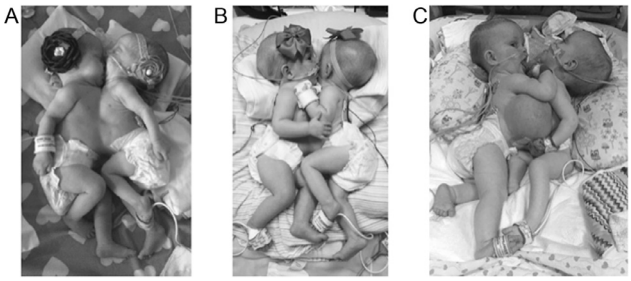


Fig. 4 – Positioning considerations for conjoined twins. Optimal upper extremity positioning was a challenge. (A) Initially the twins' arms were crossed behind the opposite twin's neck. As they grew, there became too much weight on the arm laying under the opposite twin. (B) We then placed their arms down by their sides in between where they were conjoined. (C) This space disappeared after skin expander insertion, again requiring the need to cross their arms behind the opposite twin's neck. To relieve the pressure on the arm and the skin expander, we used an air-fluidized adult-sized bed (Clinitron®) for continuous pressure redistribution and various supports such as the Boppy® pillow seen in this picture to relieve pressure on the arms.

foam mattress overlay (Delta Foam™) to protect a set of twins from hospital-acquired pressure injuries (HAPI) and were able to successfully lie them in their mother's and caregivers' laps for bonding and social interaction with the foam overlay still in place. Foam dressings (Mepilex® Lite, Mölnlycke Health Care, Norcross, Georgia) were useful in helping reduce redness to bony prominences. As the infants grew, we began lying them on a donut-shaped pillow (Boppy®, The Boppy Company, Golden, Colorado). Gel pillows were also useful throughout hospitalization in reducing pressure to bony prominences.

Repositioning and turning is imperative to preventing HAPI and maintaining comfort. We turned the twins every three hours until skin expansion, at which time we increased the frequency to every two hours as their skin integrity was more vulnerable. A key consideration in repositioning is maintaining twin identification. It is important to have the twins remain on their designated side of the bed to ensure proper identification by anyone caring for them. When turning, we flipped the orientation of the twins' heads from HOB toward the foot of the bed so twin A and B remained on the same side of the bed throughout the hospital course.

As the twins underwent tissue expansion to prepare for surgical separation, they began to require more frequent and extensive skin assessment. Skin integrity is compromised during this phase as the skin stretches. We found with two sets of conjoined twins that an adult air fluidized bed offers increased skin protection over standard NICU beds because of its ability to continuously redistribute pressure. Ongoing assessment and repositioning at least every two hours when the skin is being expanded is essential to preventing HAPI. A custom electronic documentation template was developed around the twins' unique needs to ensure consistent and comprehensive monitoring of skin condition, including the tissue expander sites.

Medical adhesives should be minimized over the tissue expaners because neonatal skin is at increased risk for medical adhesive-related skin injury (MARSI)[7], and the risk may be exacerbated by the skin changes associated with stretching. Foam dressings may be a superior alternative to covering the site with traditional bandages.

Procedures

When preparing conjoined twins for procedures, NICUs must anticipate additional complexities and resource requirements. Primary nurses were effective at optimizing preparation for procedures to meet the unique needs of conjoined twins with the goal of minimizing complications. Pre-procedural preparation included:

- Validating adherence to *nil per os* (NPO) schedules for each twin.
- Determining optimal location for intravenous access, considering anticipated patient position, skin integrity, and the ability to properly secure IV at a given location.

Fig. 5 – Orthotic devices. Specialty equipment to aid in achieving developmental milestones were an important part of providing comprehensive care for conjoined twins. (A) The tummy time table allowed a set of conjoined twins to alternate time spent prone. (B) The conjoined twin swing allowed for a growing set of conjoined twins to be upright and somewhat independently mobile, similar to the commercially available jumpers used for individual infants. Time spent in the swing was pleasing to the infants, their family members and the staff caring for the twins.

- Gathering all required equipment (two or more of everything, as well as additional labeling supplies).
- Determining the best method to label all lines, equipment and patients to maintain consistent identification for the teams performing the procedure.
- Ensuring appropriate number and roles of staff present for each patient, considering the need for additional staffing support if sedation or narcotics are necessary.

Color coding was essential during all procedures. For most procedures this was achieved by using colored self-adherent wrap to create an appropriately colored bracelet around each limb on each twin. For separation surgery these would need to be removed, so fingernails and toenails were painted in the corresponding color, allowing for accurate identification throughout separation. All lines and portable monitors should be color coded as well. Using a consistent system of color-coding allows all team members in any procedure to identify each patient correctly.

During a procedure, primary nurses are often used as a source of clinical information and can assist in patient identification. They also provide comfort and offer advice on how to calm the patients during the procedure. Lastly, they can communicate with the unit and charge nurse of changes in condition that could require adjustment to the staffing or resources needed during recovery. After the procedure, primary nurses help transition the patients back to their unit and usual routine. They may also be able to identify subtle changes in clinical status that may not be recognized by providers less consistently involved in their care.

Nursing handoffs

Nursing care handoffs are intended to ensure key patient data are communicated in an overall effort to foster patient safety[8]. For conjoined twins, we found it beneficial to discuss the overall anatomy during each handoff. During this time, both the oncoming and off-going nurses should identify the infants by their designated color, trace all color-coded lines to each infant and verify all infusion rates. Established emergency procedures must be reviewed, stressing the importance of using color codes as patient identifiers in emergency situations. Pre-calculated code medication sheets remained secured at the foot of the bed for ease of accessibility.

Measuring intake and output

Measuring intake and output can be a challenge with conjoined twins due to the complexities of their anatomy. A set of thoraco-omphalo-ischiopagus conjoined twins had fused genitalia, making it impossible to discern which twin was having urine output. Therefore, the diaper was weighed and divided by two, with each twin getting credit for half of the output. Separate pelvises in a set of thoraco-oomphalopagus twins enabled each twin to wear a diaper, allowing for discrete measurement and documentation of each twin's output accordingly.

Fostering maternal bonding and attachment

Becoming a mother involves a complex, interactive cohort of physical, psychological and behavioral changes that affect bonding and attachment[9]. Having a child in the NICU can alter or delay a mother's successful transition to her new role. In the case of conjoined twins, the effects of the NICU environment are further magnified by the babies' complex anatomy as well as their intensive environmental, medical and nursing care needs. Attaining the maternal role involves four distinct psychological tasks: ensuring safe passage, binding-in to the child, learning to give of oneself, and gaining acceptance by others[10]. This section will postulate the specific effects of having conjoined twins and outline strategic ways to overcome these and maximize attachment and bonding.

An essential component of attaining the maternal role is binding-in to the infants through direct physical interaction, encouraging talk, touch, physical nurturing and holding as early and as often as possible. With conjoined twins, enabling such interaction may be more feasible when the babies are younger and smaller in size, making the early days and weeks crucial in optimizing maternal confidence. Openly discussing the babies' behaviors and preferences *in utero* as they compare to the NICU (e.g., specific sleep and wake times, active kicking, hiccups after feeding) can help a mother emotionally connect the babies in the NICU to the babies in the womb. Using the babies' first names and ascribing unique personality traits to each infant during care times is key in establishing them as individuals. NICU providers must remember to treat the babies as they would any other infant with a gentle and loving touch, a calm and reassuring tone, smiling and eye contact.

Achieving acceptance by others may feel increasingly difficult to the mother of conjoined twins as multitudes of consultants, press outlets and curious passers-by seek to gain insight into this incredibly rare condition. The care team is tasked with ensuring a sense of normalcy, dignity and humanity throughout the babies' hospitalization. Engaging family members in bathing, massaging and hair brushing provides comfort not only to the babies but to the parents, who may find it difficult to feel useful in the care of their hospitalized infants. Provision of clean linen becomes more meaningful with the use of gender-specific sheets or blankets that mimic what might be found in the home nursery. Infant clothing that is modified to fit conjoined twins can promote parental pride in the babies' appearance while encouraging active engagement and adoration by caregivers and NICU providers. If the babies' clinical status does not allow dressing, accessories such as hats, socks and hair accessories can serve the same purpose while promoting individualization to each infant's personality. It is important not only to verbally affirm the importance of the babies in the lives of NICU professionals, but also to verbally recognize and applaud the caregiving efforts on the part of the mother. This affirmation is important not only in immediate bedside care but in external activities that promote maternal/infant health, such as pumping breast milk, eating a healthy diet, and resting when able.

In the NICU, ensuring safe passage centers largely on attainment of knowledge. Mothers in the NICU feel an

inherent urge to nurture their infants yet may not know specifically how they can be involved in providing such care. Early and frequent engagement in caregiving activities fosters maternal role attainment by increasing maternal comfort and confidence in knowing how to care for their hospitalized infants. NICU professionals must also recognize the need to provide knowledge to mothers that is specific to the infants' clinical condition, plan of care and prognosis. Left unguided, mothers may turn to unreliable or inaccurate sources for information on their infants' trajectory. This type of information-seeking can be counterproductive by promoting worry, fear or false beliefs about what will happen to their babies. Rather, the NICU professional must engage actively with the mother in providing reputable sources for information while facilitating connection with the clinical team that will oversee the
babies' care. A direct contact for information, such as phone number or email address, as well as active engagement in patient rounds can help satisfy the need for specific clinical knowledge.

The NICU environment has perhaps the most profound effect on the task of learning to give of oneself. New mothers may feel vulnerable, physically exhausted and emotionally depleted. The magnification of these feelings during a NICU stay cannot be underestimated. It is essential that NICU providers take on the task of "mothering the mother" through active listening, authentic presence and caring behaviors. Ensuring the mother is physically comfortable by offering water, seating and rest are as important as ensuring the mother feels heard and valued as the expert in her babies' care. NICU professionals must ensure their body language reflects the importance of the maternal role through eye contact, conversation, and physical presence at the bedside. A thorough understanding of the transition to motherhood allows the NICU care provider to design, implement and evaluate the effectiveness of interventions to promote bonding and attachment.

NICU multidisciplinary team care coordination

Ongoing care of conjoined twins requires cooperation from a large number of disciplines that must work together to plan for and respond to the unique challenges encountered. Coordination of this care should be seamless and requires regular meetings of the care team. We found team meetings to be most beneficial when implemented prenatally. The goals of team meetings included:

- Update all team members to the condition and plan for the conjoined twins.
- Identify current and potential concerns.
- Determine strategy and action plan for addressing concerns.

Members of this team are listed in Table 2a. The group was co-led by a physician and nursing leader. The physician leader was involved in the care of the twins throughout hospitalization and served as an advisor for each set of conjoined twins. The physician leader tracked the clinical course of the twins, helped coordinate with the other specialty teams involved including the surgical and radiological teams, and represented the NICU team at other medical multidisciplinary meetings. The nursing leader was a clinical nurse specialist or nurse manager that was familiar with the topics that would need to be discussed and could offer direction to group members. In our experience, having both a physician and nursing leader working together as group leaders was key in the success of the multidisciplinary team. Team leaders must demonstrate systems-thinking and clear, effective communication throughout the care coordination process in order to maximize the outcome of team efforts.

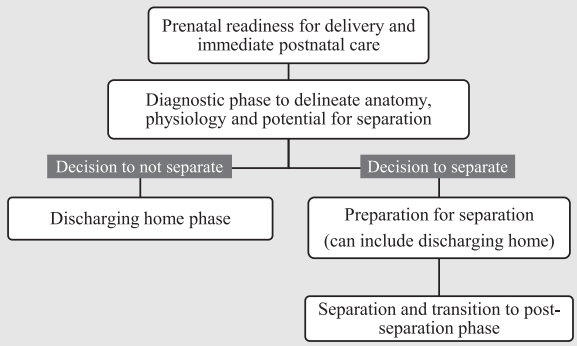
The framework for the meetings and discussion were divided into phases of care as depicted in Table 2b. These phases of care helped delineate the issues that needed to be identified and discussed and provided a context for developing solutions. Task owners were assigned as needed to identify or implement such solutions, with those individuals being

Table 2 – Team members and phases of care of the interdisciplinary care coordination team. Interdisciplinary care coordination was an essential component of providing comprehensive care to conjoined twins. (A) Team members involved in the care coordination team are listed. Each discipline served a unique but equally important function in addressing the holistic needs of these complex patients. (B) Care coordination efforts were focused into phases of care so as not to become unnecessarily detailed or burdensome in advance of future issues. Utilizing a phase-based approach helped focus the team on the tasks currently at hand while remaining conscious of potential future considerations and implications of current decisions.

Table 2a.

Primary nurses
Nursing leaders (e.g., nurse managers and above)
Clinical nurse specialist
Neonatal nurse practitioners
Physicians
Dietician
Social worker
Physical therapists
Occupational therapists
Child life specialists
Family Advocacy
Public relations team members
Care managers
Chaplain

Table 2b.



responsible for reporting updates and bringing forth barriers to success at subsequent meetings. Careful record-keeping of the group members' activity helped ensure efforts were systematic and without duplication. These records also served as a guide for planning the care of future sets of conjoined twins.

Meeting frequency remained flexible and increased or decreased as the needs of the patients evolved. During busy times such as ensuring prenatal readiness, meetings were held weekly. However, during other phases such as preparation for separation, meetings were less frequent. Although the group leaders primarily determined the meeting frequency, any member of the team could request a meeting if they believed it was needed.

Through this care coordination effort, our team was able to proactively identify and address potential or developing challenges. This helped minimize disruption to the care we provided for the conjoined twins and the support we provided to their families.

Conclusion

A multidisciplinary team with ongoing collaboration offers an effective approach to coordinate the efforts and address all the unique challenges encountered with the care of conjoined twins. Nursing care, and especially the care of primary nurses, is central to the success of this coordination. Nurses caring for three sets of conjoined twins demonstrated autonomy, ingenuity and passion to promote optimal outcomes for these rare and complex patients. By providing strong, supportive leadership and empowering nurses to individualize care at the bedside, NICUs can readily adapt to the unique needs of conjoined twins.

Author contributions

All authors contributed to writing the content of the manuscript. Jonathan Davies and Alexandra Luton edited the manuscript.

Disclosures

Mrs. Luton reports current employment as a paid consultant to DandleLION™ Medical but was not serving the company in any capacity during her clinical contribution to this work. The remaining authors report no potential conflicts of interest

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