

Managing many hospital moves with an infant



What is this study about?

Caregivers (refers to parents and others caring for the child) of preterm and ill infants often have to transition (move) between more than one hospital or healthcare setting in the first few days, months or year of their child's life. These moves are difficult. Many caregivers are still getting used to the idea of being a caregiver and learning how to care for an infant. Learning how to meet their child's healthcare needs makes this time more difficult. Caregivers of preterm or ill infants face high levels of stress, anxiety, depression, and grief. To understand how such moves affect caregivers and families, the study team:

- did a scoping review (broad search of the research) to understand parents' needs during their preterm infants' healthcare transitions
- gained a better understanding of caregiving roles, sources of stress, and sources of support

What is a 'transition'?

In this study, transitions are moves between different places or roles. Caregivers and infants in this article are moving from one healthcare setting to another. They are also moving into the role of caregiver of a premature child.



What is a 'scoping review'?

A scoping review looks at many types of studies to better understand a topic. It may include published (e.g., journal articles) and unpublished work (e.g., posters, presentations, other documents).



What did the study team find?

In the included articles, caregivers shared that they had a **stressful experience using and dealing with the healthcare system**, and were afraid of the unknown for their child. Caregivers felt that moving to new healthcare settings often increased what the team called **parenting at a distance**. This meant a separation between the caregiver and their child, both physically and emotionally. Physical distance included the hospital or clinic, for example, being far away from the family's home and day-to-day life. Emotional distances included caregivers not being able to touch or hold their child because of hospital rules or equipment.

Sources of transition stress:

- (1) not being part or aware of decisions about their child's care;
- (2) not receiving enough information to get ready for future transitions;

- (3) differences between how hospitals or clinics carry out activities (e.g. provide care); and
- (4) not knowing what to expect in a new care setting

Sources of transition support:

- (1) being aware of what is happening with their child and feeling included in decision making with the healthcare team (particularly if there was a person to connect with regularly in each new setting);
- (2) healthcare team members knowing and understanding what they are going through;
- (3) feeling ready to deal with future moves (e.g. seeing the setting ahead of time, having information early on); and
- (4) receiving support from peers, family and friends (e.g. babysitting siblings, having caring conversations)

“**From a caregiver who read this study:**

[The article] highlighted feelings and fears experienced by us then; but we continue to face each and every day given [our son’s] current state. Transitions never stop and I appreciated the article highlighting the many transitions. Not just the hospital to hospital transition.”



What this means for caregivers

With all the attention focused on their infant’s health and wellbeing, caregivers’ needs may get pushed aside. This study supports that caregivers’ wellbeing and feeling involved, ready and supported, can help them to better care for their child.

Here are some tips from families at Holland Bloorview who have experienced similar transitions:

- ✓ Know you are not alone. Many caregivers in this situation feel fear, stress, and may feel disconnected from their child.
- ✓ Find someone on your healthcare team with whom you feel comfortable and trust. Before you move to a new site and new team, ask if they can put you in touch with someone from the new team.
- ✓ Don’t be afraid to ask for what you want. Try planning ahead for a future transition, setting up a visit to the new site or asking for information early on.
- ✓ Reach out to your family and friends for support to help you, your child, and your family.

Tips for speaking to your healthcare provider:

Are you getting ready for a healthcare transition or know someone who is? Consider asking:

- to meet the new team
- for a tour of the new site
- for information
- to speak to a team member that can help explain things that may not be clear



For more information

Find the [abstract here](#) or visit your local library:

Ballantyne, M., Orava, T., Bernardo, S., McPherson, A.C., Church, P., & Fehlings, D. (2017). Parents’ early healthcare transition experiences with preterm and acutely ill infants: a scoping review. *Child: Care, Health and Development*, 43(6), 783–796. doi:10.1111/cch.12458

- View [Dr. Ballantyne’s researcher profile](#)
- Check out Holland Bloorview’s [Care for the Caregiver Hub](#)

