

# What is the right approach to infection prevention and control for children living at home with invasive devices?

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Soto Carmen, Tarrant Carolyn, Dixon-Woods Mary

Social Science Applied to Healthcare Improvement Research (SAPPHIRE) Group  
Department of Health Sciences  
University of Leicester

Corresponding author:

Dr Carolyn Tarrant

Social Science Applied to Healthcare Improvement Research (SAPPHIRE) Group

Department of Health Sciences

University of Leicester

22-28 Princess Road West

Leicester, LE1 6TP

Tel: +44 (0)116 252 3217

Email: [ccp3@le.ac.uk](mailto:ccp3@le.ac.uk)

## **Summary**

Infection prevention and control (IPC) efforts have primarily focused on acute care. Children with invasive-devices living at home are at risk of healthcare associated infection (HCAIs), and providing safe care places special demands on their family. Evidence suggests that the majority of HCAIs in the hospital setting are preventable. How families maintain IPC practices in the home remains poorly understood. Nor is it apparent how children and families balance infection control with pursuing a normal childhood. Understanding how children, families, and professionals work together to achieve safe care is essential to grasp the complexity of these challenges.

## **Increasing numbers of children with invasive devices living in the community, at risk of infection**

Infection prevention and control (IPC) efforts and research thus far have primarily focused on the acute care setting and on the behaviours and practices of healthcare workers, but recognition is increasingly growing that infection risks are not contained within organisational boundaries, and that many individuals who are not healthcare professionals may be involved in managing those risks. Children living long-term with invasive devices such as central lines, gastrostomy tubes, dialysis catheters, and tracheostomies are an example of a patient group that is particularly vulnerable to infection who may be cared for primarily at home by family members.<sup>(3,4)</sup> The number of these children appears to have increased dramatically in recent years,<sup>(5-10)</sup> largely due to changing patterns of care for children, and therapeutic advances in neonatology, oncology, cardiology, and transplant medicine (to name but a few).<sup>(9,11-14)</sup> Caring for children in their own homes has significant benefits for their quality of life, but places special demands on families, who have to deliver complex care.<sup>(15-18)</sup>

These children have a high rate of unplanned hospital admissions for infective complications, causing disruption to the child and their families.<sup>(19,20)</sup> Infection and its possible consequences are a source of pervasive anxiety and fear for families, given the risks associated with long-term antibiotics and vulnerability to sepsis.<sup>(21-23)</sup> The implications for health services are also significant: it costs almost \$70,000 to treat a central line infection in a child.<sup>(24,25)</sup> Yet the rise of homecare for children with complex medical needs has not been accompanied by a parallel rise in the recognition of these risks, nor in the development of strategies to mitigate them.<sup>(26-29)</sup> How best families and children can be supported in preventing and controlling infection in the community remains poorly understood

## **Advances in prevention and control of healthcare-associated infections**

The idea that healthcare associated infections (HCAI) might be largely preventable is a relatively recent one.<sup>(30)</sup> The success of programmes targeting HCAs has dramatically changed the perception that HCAs are inescapable, so much so that by 2012, NICE guidance in the UK was referring to HCAs as “avoidable events to be viewed with a “no-tolerance” attitude.”<sup>(31)</sup>

What makes reductions in reported rates of HCAI especially remarkable is that they have been achieved largely without any new advances in technology. Rather, these successes have come about by implementing already-recognised approaches in a systematic and structured fashion.<sup>(32)</sup> The implementation of care bundles – which group together evidence-based interventions that have to be consistently performed for every patient, every time – has produced impressive results in adult intensive care units as well as for a variety of HCAs in the hospital setting, for instance.<sup>(33,34)</sup> Importantly, the research evidence suggests that the success of the bundle approach is likely to rely as much on understanding

the human and structural factors in which these interventions take place as on the evidence base for the technical components.<sup>(35,36)</sup>

Much of the success to date has been reported in adult populations. Despite trialling the care bundle approach, HCAs remain a challenge in the paediatric population.<sup>(37,38)</sup> The reasons for this are complex. The evidence-base for infection control measures in paediatrics is relatively sparse, and tends to be derived from adult medicine.<sup>(37,39,40)</sup> The paediatric context also has unique features: the organisms seen in paediatric HCAs are different from those seen in adults, the indications for inserting a device in a child can be very different from those in an adult, and such devices may be left in for longer periods to avoid psychological distress or technical difficulties.<sup>(37,41,42)</sup> What works for adults may not work for children, as illustrated by the example of central line infections in paediatric intensive care units, which seem to respond much less well to improved compliance with infection control procedures during insert than their adult counterparts,<sup>(37)</sup> instead depending much more on quality of care during maintenance.<sup>(37)</sup> It thus follows that the care of an invasive device throughout its use, whether in hospital or at home, is likely to be important in prevention and control of HCAs.

## **The challenges of children with invasive devices at home**

If reducing paediatric device-related HCAs infections within hospitals is problematic, the challenges are multiplied when children are mostly cared for at home. It remains unclear to what extent solutions developed in the highly controlled and bounded environments of acute hospitals and administered by health professionals can be transferred to the care of children in the community, whose care-givers are likely to be multiple and rely largely on families themselves.

These children interact with a complex network of people, both clinical and non-clinical, who are involved in delivering medical and nursing care in a range of different

environments. Families who care for children at home strive to deliver safe care whilst trying to maintain a degree of normality for their child and the wider family.<sup>(43)</sup> Professional support enables families to experience some degree of ordinary childhood. Children who live in the community will go to school, birthday parties, and playgrounds. Of necessity, this means that technical procedures perhaps ideally performed in the safe confines of a sterile environment are undertaken in homes, schools and other settings. Central lines are accessed in school rooms; intravenous medications are drawn up in kitchens; tracheostomy and gastrostomy tubes are handled and changed in bedrooms and living rooms. The elements of structural control which can be applied in the bounded setting of the intensive care unit are unlikely to be feasible in people's own homes. The interventions reached for by policy-makers and managers when seeking to encourage staff compliance with IPC standards – such as a zero tolerance approach to breaches in a care bundle, or financial incentives - have no relevance in this situation. Rather, carers must establish what risks they are prepared to accept in pursuit of this normality, a balance which may be unique to each family.

Also unclear is whether the approaches developed for supporting adult patients to take care of their own central line in the community - for example through intensive education and training programmes - are transferable to children. Though some of these programmes demonstrate positive effects, they also require significant commitment from patients and a taking on of a responsibilities that some find difficult.<sup>(44)</sup> Parents may be prepared to take on this additional responsibility on their child's behalf, but children's behaviours are not the same as adults.<sup>(29)</sup> Adults are unlikely to chew their Hickman line, or run away during a dressing change. Adult patients do not (usually) have friends who pull on their gastrostomy tube nor siblings who want to share a bath with them.

To deliver safe care of invasive devices in the community, we must first pay attention to the challenges that families face in their everyday lives. More than this, we must also appreciate the resources that families develop in order to meet these challenges, and what factors may hinder this capacity.<sup>(45)</sup> Evidence suggests that families can develop expertise in caring for an invasive device. This is likely to be highly skilled, contextually-specific expertise which is relevant to their unique position as parents and carers of their child. Families develop complex working relationships with the professionals involved in the care of their child, and maintaining effective relationships is critical for families to feel supported in their role as primary carer for the child and their device.<sup>(46)</sup>

As the number of children receiving complex care in the community expands, it is increasingly important to recognise the realities of care provision by families, and complex nature of the interaction between families, professionals, and the everyday environments in which care is provided; the challenges that families face; the resources and resilience that they bring to meet these challenges; and what kind of support is best suited to meeting their needs. It is not sufficient to approach the problem of IPC in children with invasive devices solely from the perspective of healthcare workers. Seeking the views of families, children, and other stakeholders who play a role in the daily life of children with invasive devices is critical to provide an authentic perspective on the complexity of the problems faced. Only then can we design services which truly meet the needs of children and young people in the community, and which adequately support the families and professional services who care for them to minimise the risks of HCAs.

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