

Partnerships between families and professionals:
Managing risks of infection in children with
invasive devices

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by

Dawn Carmen Eynon Soto

MBBS, BMedSci (Hons), MSc (Hons), MRCPCH

Department of Health Sciences

University of Leicester

For Adam,

whose patience and insight helped me to see things differently

Adam Bojelian

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ABSTRACT

Partnerships between families and professionals: Managing risks of infection in children with invasive devices.

Dawn Carmen Eynon Soto

Children with an invasive device are at risk of serious infection and its complications. Though studies suggest that strict adherence to infection prevention and control (IPC) practices can reduce device-related infections, this research has mainly taken place in hospital settings where care is performed by trained professionals in dedicated environments. Little is known about device care for the growing number of children with invasive devices who live at home, where the care of the device is undertaken by a complex network of family members and professionals across multiple settings. This study seeks to explore how device care is performed outside formal healthcare settings, and investigates how families and professionals work together.

Semi-structured interviews were carried out with families and professionals who were recruited using a purposive sampling method. Eighteen mothers, four fathers, and eleven children participated in family interviews; 20 interviews were undertaken with professionals from a range of disciplines. Data analysis was based on the constant comparative method.

Analysis revealed that families are engaged in a complex process of trade-offs as they try to balance the demands of device care while maintaining a normal life for their family. Though avoiding infection is a key priority for families, it is not the only one: maintaining a sense of “normal life” is another goal. Maintaining compliance with IPC practices requires much work and expertise on the part of families, yet this may not be fully recognised by professionals. Some professionals recognised the expertise of families, and worked with them to achieve a shared goal of maintaining IPC in the context of everyday life – a form of co-production. Co-production offers a model for children, families and professionals to work together in a way that makes best use of their expertise and skills, responding to individual families’ priorities, and tailored to their particular circumstances.

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ABBREVIATIONS

CINHAL	Cumulative Index to Nursing and Allied Health Literature
CLABSI	Central line associated bloodstream infection
HCAI	Healthcare associated infection
ICU	Intensive care unit
IPC	Infection prevention and control
NHS	National Health Service
PEG	Percutaneous endoscopic gastrostomy
PICC	Peripherally inserted central catheter
PN	Parenteral nutrition
REC	Research ethics committee
SWAN	Syndrome without a name

1 **Background**

1.1 **Introduction**

Healthcare associated infections (HCAIs) are a major concern for modern medicine. Attention has largely been focused on the hospital environment, and on the actions of healthcare professionals in preventing HCAIs. Particular focus has been paid to reducing infections associated with invasive devices, used to support increasingly complex medical care. These endeavours have had a significant positive impact on reducing HCAIs in the hospital setting. In this thesis, I suggest that attention now needs to turn to addressing HCAIs in the home environment. The thesis focuses particularly on children with invasive devices, who are now, to a far greater extent than previously, cared for at home. These children are particularly at risk for HCAI, and the consequences for children, families, and health services are significant.

I begin this chapter with an overview of the problem of healthcare-associated infections (HCAIs) in the hospital setting and the efforts that have been made to reduce HCAIs, in particular device-related infections in this setting. I then present a systematic, narrative review of the evidence for infection prevention and control (IPC) in children with invasive devices living at home, focusing on central-lines. Drawing on the literature on patient safety, I explore the role of patients and families in caring for invasive devices and maintaining IPC in the home.

I argue that achieving success in controlling device-related infection in the home requires sound understanding of the roles that children, families and professionals play in maintaining device care in the family home and wider community. This chapter summarises the relevant literature, showing how despite significant success in addressing HCAI in the hospital setting, strategies to achieve the same outcomes in the community are under-researched while the influences on compliance with device care are poorly understood. These voids in the literature provide an important motive for the thesis.

1.2 Addressing HCAs in the hospital setting – lessons for success

In this section I give an overview of the progress that has been made in addressing HCAs, with particular attention to device-related infection.

1.2.1 The significance of HCAs

HCAs are infections acquired as a result of treatment or contact with healthcare services, either in healthcare settings (such as hospitals) or in the community.(1) HCAs have a significant impact on patients, resulting in increased morbidity, prolonged hospital stays, and even death.(2) They are not uncommon – estimates from the UK are that between 6 – 9% of patients in acute hospitals will acquire a HCAI.(3,4) They have a significant impact on healthcare systems – it has been estimated that the annual cost to the US healthcare system is almost \$10 billion.(5) HCAs are therefore an important issue for both patients and healthcare systems.

The recognition that healthcare can result in infection with significant consequences is not new.(6) However, the successes of modern medicine have made these risks more apparent: medical techniques and procedures are increasingly complex, while patients are surviving for longer than before.(7,8) Infections associated with the use of invasive devices are a particular cause for concern.(9)

Treating HCAs is costly and time-consuming for healthcare services, and the impact on individual patients is considerable. Current strategies for treating HCAs rely on the use of antibiotics, contributing to the growing problem of antibiotic resistance.(8,10,11) Attention is therefore turning to prevention, rather than treatment. Recent years have seen a drive in institutional policy to reduce the incidence of HCAs in hospitals (12,13) with dramatic progress seen in adult settings.(14)

By the end of the twentieth century, HCAs were often viewed as an inevitable consequence of modern healthcare.(4,8) In the year 2000, a National Audit Office report on hospital-acquired infections in the NHS commented that “not all hospital-acquired infections are preventable”(4), suggesting that up to 30% of HCAs could be preventable, a figure repeated by the Chief Medical Officer’s report in 2002.(8) Policy

at this time was largely focused on strategies to identify and manage infections, rather than preventing them.(7)

There is now evidence that the systematic implementation of established evidence-based practice can decrease infections previously perceived as an inevitable part of medical care. Infections are increasingly seen as preventable adverse events to be viewed with a “no tolerance” attitude.(15) Some forms of HCAs, such as central line associated bloodstream infections (CLABSIs) have even been described as “never events” (16), although no intervention has yet been shown to completely eradicate line-infections.

1.2.2 What works to reduce device-related infections?

Efforts to reduce the incidence of infections associated with invasive devices have received particular attention. Invasive devices are devices used to support medical care that are implanted into a patient. These are life-enhancing and often life-saving interventions, and are used in patients with a wide variety of medical conditions. They include tunnelled and implanted central lines, tracheostomies, and gastrostomies. Invasive devices are used to support medication administration, blood sampling, feeding, and ventilation. Notwithstanding their many benefits, invasive devices are strongly linked to the development of HCAs. The devices breach the integrity of the skin and tissues that would normally form a barrier to bacteria entering the skin; microscopic biofilms of bacteria form on the surface inside and outside the body, and the number of bacteria needed to produce an infection is greatly reduced in the presence of a device.(17) Simply having an invasive device is in itself a risk for developing HCAs.(18) Some HCAs (such as bloodstream infections and pneumonias) are rarely seen in the hospital setting unless an invasive device is also present.(2,19)

The prevention of device-related infection has focused on three principal areas. First, good hygiene practices such as the cleanliness of the healthcare environment, handwashing, the use of personal protective equipment such as gloves and aprons, and ensuring that an aseptic technique is used when devices are inserted and maintained.(8) Second, revisiting clinical decisions to ensure that devices are only inserted when necessary and are removed as soon as possible.(20,21) Third, the development of

technical innovations which aim to impede the growth of bacteria. These include a myriad of measures such as the use of devices coated with antimicrobial agents or lined with silver (22,23), dressings impregnated with antiseptic solutions (24), and the use of specific antiseptic agents to prepare the skin before device insertion.(20,25,26) Although these interventions have been shown to have some impact on the incidence of device-related infections, the benefit from individual interventions has been modest.(22-25,27)

A different approach to infection control and prevention has resulted in a dramatic reduction in the incidence of HCAs in the hospital setting, without the introduction of any new technological innovations.(14,28) Using a “care bundle” of evidence-based technical interventions alongside strict adherence to hygiene practices has resulted in significant reductions in device-related infections.(14,29,30) The care bundle approach is now the basis of many attempts to prevent device-related infections.(31,32)

Notwithstanding the success of the care bundle approach, not all centres have seen the same reduction in device-related infection.(29) The variation in outcome suggests that implementation is as important as the evidence-based interventions which form the basis of the care bundles (33), and there is growing evidence that context is important.(34,35) Strict adherence to all aspects of the care bundle is essential if device-related infections are to be prevented (29,36), thus the engagement of staff who are responsible for carrying out device care is key. Centres which have had success in reducing device-related infection have also made systems-wide changes in their approaches to HCAs, including an increased awareness of the importance of HCAs; engagement of clinicians to support changes in decision-making; peer to peer dissemination of credible information; a strong bond between the team and individual unit; and a multi-disciplinary approach towards infection control.(14,36,37)

Although there have been examples of hospital initiatives successfully reducing the incidence of device-related infections by using established best practice (without new technological innovations) much of the attention has been focussed on adult patients in ICUs (Intensive Care Units). Addressing HCAs in different populations and in different settings, such as children at home, has proved more challenging.(35,38,39)

1.2.3 Addressing device-related infections in children

HCAIs in children are different from those seen in adults.(8) Children with invasive devices are at increased risk of infection through multiple sources: the nature of their disease; the device used to provide treatment; prolonged stays in hospital and contact with healthcare; and frequent use of antibiotics leading to drug resistance.(40-45)

As in the adult setting, the evidence from paediatric ICUs demonstrates multi-institutional implementation of current best practice results in a decrease in device-related infections.(39,46-48) However, there are important differences between adult and paediatric HCAIs. The indications for inserting and using invasive devices in children are different from those in adults – for example, a central line may be kept in for longer to minimise distress to the child rather than for purely clinical indications.(39,49) Designing care bundles to address device-related infections in children has proved challenging as the evidence for individual components is relatively sparse.(27,50,51) Thus, the “best-practice” included in care bundles may be based on expert consensus rather than definitive evidence.(51,52) Implementation of care bundles has revealed further differences – there is some evidence that careful adherence to the care bundle during ongoing care and maintenance of the central line, rather than during insertion, appears to be mainly responsible for the decrease in CLABSIs in the paediatric ICU.(39) Overall, the mechanism of the success of care bundles in paediatric device care remains poorly understood.(47)

Despite the differences between adult and paediatric care bundles, successful initiatives share some similarities. Implementing care bundles in paediatric settings is improved where deliberate attempts are made to engage the staff responsible for carrying out device care (39) and where high levels of compliance with all aspects of the bundle are achieved.(53) Ensuring care providers are engaged and able to deliver the same strict adherence to care bundles outside the hospital setting may pose new challenges, especially when those care-givers may not be health professionals.

1.2.4 Addressing device-related infections in the home setting

Hospital-based initiatives have demonstrated success within the healthcare environment and when working with large teams of healthcare professionals. This is a very different

environment from the patient's home, and addressing device-related infections outside the confines of the hospital poses unique challenges. Policy-makers are beginning to recognise that tackling HCAs in the community requires particular attention. Here, I give an overview of the relevant policy and discuss the specific challenges to reducing device-related infections in the home setting.

Early policy recommendations relating to the reduction of HCAI were focused on hospital care.(4) Subsequent policy documents demonstrate a growing realisation that HCAs are not confined to hospitals. In 2002, the Chief Medical Officer published a report which recognised that HCAs were not solely the responsibility of hospitals, but were influenced by patients' contact with, and need for health services. However, the framework described to support infection control remained predominantly hospital-based.(8) Although acknowledging the contribution of the wider environment to HCAs, attempts at infection control and prevention remained focused on formal healthcare settings in subsequent publications.(7) Where guidelines have centred on healthcare delivered outside of hospitals, little attention has been paid to the specific context of care provided in families' own homes or in the wider community.(54) Guidelines designed for use in acute hospitals were transferred to the community without consideration of the particular challenges and factors which influence device care in this environment. Notwithstanding the acknowledgement that the community is an important focus for preventing device-related infection, recent guidelines remain framed mainly for structured and bounded healthcare settings.(1,2)

It is not straightforward to replicate achievements of the ICUs in reducing infection in adults with invasive devices to the care of children with invasive devices at home. In ICUs, clinical governance and regular review and audit of standards are key to maintaining infection control (1,4,14): these are unlikely to be relevant or achievable in the community setting. Similarly, the strong focus on the importance of surveillance and feedback of infection rates to clinicians and healthcare workers has limited applicability when the denominator is one patient rather than a thousand.(2)

In the case of HCAs in the community, the team of caregivers includes not only professionals, but also patient, family, and wider social network. Thus in order to address HCAs in the community, attention must also be paid to the family and informal

carers in the home, rather than focusing solely on the patient and formal care providers. This corresponds well with child health care where patient and family are regularly considered alongside one another.(55) In this thesis, I use the example of children living at home with invasive devices to explore the challenges in addressing healthcare associated infection in the home.

1.3 Infection prevention and control (IPC), and children with invasive devices at home: a narrative review

Invasive devices are an important source of HCAI in children living at home. Growing numbers of children with complex needs now live at home. The consequences for children, families, and health services are significant, thus addressing device-related infection is an important patient safety issue. Although government directives and policy imperatives have resulted in a significant fall in HCAs among some groups, notably adults in the intensive care setting, achieving the same success in the child's own home environment may prove more challenging.

I conducted a narrative literature review to investigate the existing evidence for infection prevention and control (IPC) in children with invasive devices living at home. Initially, this literature review investigated central-line associated bloodstream infections (CLABSIs) rather than device-related infections as a whole. Working with a librarian, I devised a search strategy which reviewed existing evidence for infection prevention and control (IPC) in children with central-lines living at home. Databases searched included MEDLINE (the bibliographic database of the National Library of Medicine), CINAHL (Cumulative Index to Nursing and Allied Health Literature), and Scopus (a bibliographic database which includes medical, nursing, and social science publications). Using a range of different databases meant that I was able to draw on research from different disciplines in the field. I used automated alerts to ensure that I was aware of new research in the field. I also searched through UK government databases, and through the publications of non-governmental organisations working with children with complex medical needs such as the National Children's Bureau. An example of the search as run through MEDLINE is given in Appendix A.

Scoping the literature on CLABSIs revealed a paucity of existing research. At the same time, changes in local practice meant that fewer children were having tunnelled central-lines inserted. The reasons for this are discussed further in section 2.4.4. Reviewing the background literature on HCAs, it became clear that other medical devices were an important target for IPC measures. The literature search was therefore expanded to include other devices, such as totally implanted central venous access devices (commonly referred to as Portacaths), tracheostomies, and gastrostomies. Further details about these devices are found in *Table 1.1*.

1.3.1 Children living at home are at risk of device-related infection

The number of children at risk of device-related infection in the family home is increasing.(56-58) Advances in neonatology, cardiology, and oncology (amongst others) mean that more children are surviving illnesses that would previously have been fatal. More children are now living with long-term medical conditions with complex care needs, including increased use of invasive devices.(59) While there is no centralised record of these children, it was estimated in 1999 that at least 6000 technology-dependent children were living in the community in the UK.(60) Increasingly, children with complex medical needs receive much of their medical and nursing care in their own home.(61) The move to home care results in improved quality of life for children, and has generally been welcomed by patients, families, and healthcare professionals.(62-64) However, these changes mean that attention must turn to reducing device-related infections in this population.

Table 1.1. Invasive devices commonly used in children, and the indications for their use

Device	Description	Indication
Gastrostomy	Created by inserting a tube through the abdominal wall into the stomach cavity, allowing direct access to the stomach. The tube is then used to give a liquid feed and/or medications.(40)	Child not able to swallow food safely without risk of aspiration Obstruction in the oesophagus Delayed emptying from the stomach Supplemental feeds in children with chronic disease who require additional calories.(40)
Tracheostomy	An artificial opening is formed through the neck and into the windpipe. A small tube is inserted into the opening to keep the passageway open, and to allow the child to breathe through the tube rather than through their nose or mouth (42,43)	Structural problems in the upper airway (congenital or acquired after trauma to the airway) Children who need the support of a ventilator (e.g. neuromuscular disorders, premature infants) Other complex medical needs.(42,43,65,66)
Central venous access device	A catheter which is inserted into a large vein near the heart. In a tunnelled line, the external ports are left on the outside of the skin so that they can be accessed readily – referred to as a “central line” in this thesis.(67) A Portacath is accessed by passing a needle through the skin, and attaching an external catheter at the time of use.(68)	Minimising the pain and distress of taking frequent blood samples. Avoiding the pain and distress of repeated peripheral cannulation when administering medications and blood transfusions. Safe delivery of intravenous chemotherapy Delivering parenteral nutrition (PN) – a carefully balanced mixture of fluid, fats, carbohydrates and trace elements which allows children to receive nutrition through a vein rather than through the intestinal tract.(41,69-72)

A substantial proportion of children with complex needs requiring invasive devices will suffer infection and subsequent complications.(73-75) A common perception is that children have lower rates of device-related infection at home than in hospital (76), but recent studies have not borne this out.(77) Reducing device-related infection in children will mean investigating how care is delivered and experienced in the community.

Invasive devices are only used in children with significant medical needs who may already be at greater risk of infection because of their underlying medical condition.(8) For some children, such as those receiving treatment for cancer, the treatment itself will suppress their immune system.(78) Giving parenteral nutrition (PN) via a central line provides a nutrition-rich broth which is an ideal breeding ground for bacteria. Children who require ventilator support and tracheostomy are often those with underlying respiratory disease.(43) Children with more complex conditions requiring more than one device (such as a central line and a gastrostomy) have a higher risk of infection than children with a single device.(79) Thus children who use invasive devices at home are at risk both from the device itself, and the underlying condition which requires its use.(7,78,80)

As outlined in *Table 1.2*, such infections have a significant impact on children and their families. The fear of developing infection and its subsequent consequences places great emotional strain on families.(81) The impact on health services of device-related infection is also considerable: device-related infections result in additional hospital admissions, increased use of specialist services such as intensive care, as well as the costs of treating and removing an infected device.(10,11,73,75,77,82)

Table 1.2. Device-related infections in children and their consequences

Device	Infection	Consequence
Gastrostomy	<p>Stoma site infections can result in skin necrosis, and granulation leading to bleeding.(83)</p> <p>Complications around the site of the PEG may not be fully considered by healthcare professionals, and definitions of what constitutes a clinically significant infection vary.(84,85)</p>	<p>Granulation is associated with increased leak from the PEG site, itself a risk for further infection.(40,84,86)</p> <p>The resultant disruption to the device site causes pain to patients which impacts on their quality of life.(87,88)</p>
Tracheostomy	<p>Device site infections are present in up to a third of children with a tracheostomy.(43,66)</p> <p>Children may also develop infections at pressure sites from ventilator tubing or tapes used to secure the tracheostomy in place.(89)</p> <p>Granulation tissue – highly vascularised connective tissue which forms at wound sites – occurs in around a third of children with tracheostomy.(66,90)</p>	<p>Although common, device-site infections are poorly recognised by the medical community and relatively under-studied.(89)</p> <p>Over-granulation can lead to obstruction at the tracheostomy site which restricts the child’s airway, while the vessels in the friable tissue bleed easily when the tracheostomy tube is changed.(90)</p>
Central venous access device	<p>Bacteria can enter the bloodstream directly through an infected central line, resulting in a central line-associated bloodstream infection (CLABSI). Infections may also occur in the skin and soft tissues around the device.(67,72)</p>	<p>Bloodstream infections may result in severe infection and sepsis. (73,75,77)</p> <p>15% of children will need admission to intensive care.(73,75,77)</p> <p>Some infections can be fatal.(91,92)</p> <p>Infection may mean the line may need to be removed, interrupting treatment or vital nutrition.(93-95)</p> <p>Treating a child with a central line-infection costs over £50,000.(10,11,72)</p>

1.3.2 The challenge of reducing device-related infections in children living at home

The rise in the number of children being cared for at home, rather than in hospital means that attempts to decrease HCAs in the community are becoming more urgent.(96,97) The question then is whether interventions that are successful in hospital can be applied to community care in order to decrease the incidence of device-related infections. Strategies which have worked to ensure staff compliance with IPC in the hospital setting may not be useful for children in the community as there are substantial differences between the delivery of care at home compared to in hospital.

Device-related infections in children at home are different from those seen in hospital, reflected in the types of organisms seen.(73) The circumstances in which device-care is carried out are also different. In the hospital, ICUs are staffed by large numbers of personnel, and care is delivered in an environment designed for the purpose. At home, much of the day-to-day care of the child devolves to a small number of family members with some specialist input from healthcare professionals.(56,60,98,99) The move to the home setting results in additional responsibilities for families, not least as the complexity of care delivered in the home increases.(100) Parents have to take on nursing tasks, and become both parents and carers in the community setting.(100)

Care is undertaken in different community settings, both within the family home and in other settings such as schools.(101) As a result, children with invasive devices interact with a wide network of care providers in their local communities.(102,103) They develop complex partnerships within their communities to deal with the invasive device and manage infection risks. For example, over 97% of school-aged children who require home mechanical ventilation attend school, and just over half are in mainstream education (104) but the support that children with a tracheostomy receive at school is variable.(105) Delivering care of such complexity requires careful coordination between families and formal services that provide care for the child, as well as negotiating changing roles for all carers.(100,106)

Understanding the contribution of the range of partners involved in the care of children with medical needs that are cared for in the community is essential to ensure that services are tailored to their needs.(107) These carers may vary in their knowledge,

understanding, perception of risk and responsibility, and systems for infection control.(104,105) Thus understanding the contribution of the different partners involved in the care of the child with an invasive device is essential to address device-related infection.(107)

Despite recognition that patients, families, and professionals all have a role to play to prevent HCAIs (54), there is little to guide what these roles are or how these groups can best work together to address device-related infections in the home. Services are still largely designed from the provider's perspective rather than responding to the priorities of children and families.(108) Parents and professionals strive to maintain a level of normal childhood for children who have complex medical needs.(109) Efforts to integrate children into mainstream schools and community activities mean that children with invasive devices interact with a wide network of care providers, both within the family home and in other settings.(41,101,108,110,111) As a result, children come into contact with multiple services and carers, who may vary in their knowledge, understanding, perceptions of risk and responsibility, and systems for infection control.

Efforts to engage patients and families in patient safety initiatives can raise awareness, but this may not translate into action, or result in improved outcomes.(112) For example, some studies suggest families do not always follow basic infection control measures such as washing their hands before using an invasive device, despite receiving extensive training – yet it is not clear why this is.(113) Investigating the factors which influence families' behaviours in relation to IPC practices is essential if device-related infections are to be addressed outside of hospital settings.

Although national guidance mandates that patients and families should receive training in device care, such training is based on care delivered in formal healthcare environments (54) and may not be relevant to the challenges faced in the home. There is an assumption that attaining a high standard of care during the training period in hospital will translate to outcomes in the home.(113) However, the challenges faced by families are likely to be very different to those encountered in hospital, especially as families and professionals are keen to allow children to experience as normal a childhood as possible. Optimising device care in the home requires an understanding of the factors which influence patient and family practices and engagement.(110,114,115)

While official policy now recognises the role that patients and families can play in patient safety (54), how this role is carried out in practice is not known. This is a key challenge which my thesis will address.

1.3.3 The role of children and families in caring for invasive devices

Much of the work in preventing healthcare-associated infections to date has focused on the role of professionals. Given that this thesis sets out to characterise the perspective of child patients, families and professionals on IPC in relation to the child's invasive device, it is important that I clarify my position on the role that children and families take in caring for the device, and their role in research on device-related infections. At home, the child is usually cared for by parents and other close family members, thus parents have an important contribution to make to research on the topic. Alongside this, I take the position that children are important managers of their own care, and have a valid contribution to make to research on the topic within the context of this family network. In this section, I outline the background to this position and seek to demonstrate its basis in existing theory.

Patients and families are increasingly involved in their own care. The reasons for this are myriad and include a changing perception that patients have the right to make decisions about their own care, as well as the potential to improve medical outcomes.(116,117) Increasingly, healthcare practitioners are expected to engage with patients by sharing information, involving them in decision-making, and giving patients more control over their own health.(118) There is an ethical argument for engaging patients and families in their own health. Patients are the ones most directly affected by the outcomes, therefore it is only right that they should be involved in the process of making those decisions.(119) In the case of children with invasive devices, the reasons for supporting child and family engagement are also pragmatic. Families are responsible for delivering much of the day-to-day care of the child with an invasive device, supported by formal healthcare services. The role of children and families in their own healthcare is likely to increase in the near future as the number of children with complex conditions cared for at home rises and pressures on existing services become apparent. Children's lives are predominantly governed by the actions of adults around them, and in particular their parents and guardians.(120) National and international guidance

emphasises the importance of involving parents in decisions about the health of their child.(55,121) The health of children is largely considered to be the responsibility of adults, both in their immediate family and in the society in which they live.(122)

While the role of parents in caring for their child's health is long-established, the realisation that children have an important contribution to make is a relatively recent one.(122) Children can, and at times do, choose to act against the expressed desires of the adults who seek to amend their behaviours.(120) Children and adults can, and often do disagree in their accounts and interpretations of shared experiences.(123-125) The rights of children to express their views on their health, and to have these views considered when decisions are made that affect their health is part of UK health policy (121,126-128), and the importance of including children in decisions on their own health is increasingly recognised by the NHS, professional bodies, and non-governmental organisations.(126,129-131)

There are obvious benefits to involving children in decisions about their care: the anxiety about their care is reduced, and they feel more valued as individuals.(132) Children acquire specific expertise about health matters of which they have personal experience and which affect them directly (133), providing valuable information to practitioners.(134) Children are also ideally placed to suggest or provide pragmatic solutions to everyday challenges that arise as a result of their health needs.(108) Notwithstanding these benefits, involving children in discussions about their health poses challenges for families and clinicians.(134) I discuss the challenges of accessing the perspectives of children in health services research further in Chapter 2.

1.3.4 Patient and family involvement in patient safety

Until recently, the patient safety movement has largely neglected the role that patients can contribute to delivering safer healthcare.(135) This situation is gradually changing as healthcare practitioners and patient groups become more involved in patient safety initiatives.(136,137)

The arguments for involving patients in efforts to deliver safer care are compelling. In addition to the moral argument that patients have the right to be involved in measures to address their own safety (138), patients and families have the potential to make valuable

contributions to the field. Patients and their families are directly impacted when healthcare is unsafe, and their lives are dramatically affected as a result. Thus patients have most to gain by supporting the development of safer healthcare systems.(135,138) Patients are the recipients of healthcare, therefore they have unique insights into how healthcare is delivered and how errors can occur.(135,139) Patients are also present throughout the healthcare journey, allowing them to detect potential adverse events and intervene to prevent harm to occurring.(110,137,140)

Many challenges remain to be addressed before the contribution of patients can be utilised to its full potential. Some commentators have raised concerns that patients are not sufficiently aware of potential risks to be able to make meaningful contributions to discussions on patient safety issues.(140) Where patients do possess this knowledge, their ability to engage in safety initiatives may be limited by illness, fatigue, or stress (135,140), and some fear that their intervention will damage the relationship that they have with professionals.(139) Thus patients and their relatives may be least able to protect themselves when they are at their most vulnerable.(135,140)

Identifying who is responsible for preventing errors could become confused as the role is divided between patients and professionals.(138,140) This lack of clarity could leave patients more vulnerable: rather than seeing patients as an adjunct to existing safety measures, there are concerns that patients may be seen as surrogates for existing safety checks, particularly when professionals are over-stretched.(140) One argument is that asking patients to take on the responsibility of patient safety at a time when they themselves are under pressure may make healthcare less safe, not safer.(140) When patients do speak up, they experience difficulties in being heard and responded to appropriately by professionals.(138,139) These challenges for patients may explain why some are reluctant to get involved in patient safety initiatives, even when encouraged to do so.(139)

An alternative interpretation is that the types of initiatives that seek to involve patients do not make best use of their abilities. Rather than supporting patients to take a more active role in their own health (135), patients' contributions have largely been to observe, feedback, and modify the behaviour of professionals.(112,138,141) Even where families have been encouraged to take a more active role, such as requesting an

urgent medical review for a patient they believe is at risk, the focus is still on the actions of professionals.(110) In this view of patient safety, patients are seen as recipients of care who can be supported to speak up when they have concerns.(139)

The role of patients in these initiatives has been to prompt others to act, rather than to establish the actions that patients themselves take in maintaining their own safety. Little is known about the actions that patients or their families take to support the delivery of their own safe care.(135) Rather than focusing on measures which ask patients to seek help from professionals who may or may not respond to their concerns (138), one alternative would be to support the work that patients do in delivering their own care, and how this care can best be undertaken safely.

Translating increased knowledge and awareness into patient engagement and thence into action is influenced by numerous factors.(110) Families may not always be able to act as safety buffers in the health service.(142) Families are highly motivated to decrease adverse events, but many do not see it as their role to 'interfere' with healthcare activities. It is also possible that reducing HCAs may not be the first priority for all families when caring for a child with a serious illness.(143)

The extent to which families participate in activities to improve patient safety will be influenced by factors within the healthcare setting, such as encouragement from professionals, perceived vulnerability to adverse events, and perceived impact of events on the patient.(115) Merely having information of safe practice is not enough to ensure patient safety: implementation is influenced by the culture of the environment in which they take place.(114) When children have additional medical needs in the community, family members share responsibility with healthcare professionals for the care of their child. Parents now take on nursing tasks, and become both professionals and carers in the community setting. In itself, this workload places an emotional burden on parents.(100) Families who provide healthcare for their children are offered little respite from the emotional and physical stressors that are known to affect the rate of errors in the professionals.(140)

1.3.5 The role of patients and families in preventing device-related infection

A review of the successful approaches to date suggests some promising avenues in implementing infection control practices in the community, in particular with regard to central line care. A number of initiatives across the world have demonstrated that intensive education for patients and families can decrease the incidence of CLABSIs in high-risk groups at home, including in children.(75,96,144-147) These programmes ranged from providing education to caregivers on general hygiene and keeping the line clean (144) to more complex interventions which trained patients and families to change dressings, flush central lines, take blood samples, and connect intravenous nutrition.(96,145-147) These interventions all resulted in a decreased rate of CLABSI as part of wider improvement projects to address HCAs.

The success of these initiatives suggests that the incidence of device-related infection in children at home may be reduced by improved training and education of parents and other care-givers. However, a more detailed examination of the studies to date reveals a more complex picture. One study which set out to train adult participants to carry out technical device care alongside a programme of education suffered from low participation and a high drop-out rate. Although 115 patients were eligible for inclusion, 33 refused to participate in the project. Of those patients who chose to participate in the education programme, there was variability in the uptake and completion of the differing components. Concerns expressed by these non-participants included a belief that medical care should be “left to the professionals”, and worries about accepting the responsibility and additional burden this would place on them.(96) 12% of parents withdrew from a similar project, with anxiety, fear and a feeling of incompetence the main reasons given.(145) Conversely, some patients felt so confident in their ability to carry out technical tasks that they asked for further training so that they could take blood samples themselves.(96) The level of engagement and the tasks that each is prepared to undertake thus may vary between individuals.

Where patients and families do engage in training, this may not result complete adherence to IPC. In one study, nurses and parents received intensive training on central line care. As a result, 100% of observed in-patient encounters were compliant with the care bundle, but there was no monitoring of adherence to the recommendations outside

of the hospital.(147) Other evidence suggests that despite training, parents do not always comply with all aspects of IPC as they have other demands which are more pressing.(148)

Although it is possible to decrease HCAs in hospital settings through strict adherence to infection control practices, and institutional commitment to complying with these standards, the community paediatric setting poses different challenges. The behaviours of children, families, and professionals in relation to minimisation of HCAs at home remains poorly understood.(54,96) Patients and carers may have concerns about their ability to carry out medical tasks which fall to professionals in healthcare settings, and may be anxious about the additional responsibility these tasks bring.(96,145)

Participants who initially agree to undertake technical tasks normally performed by healthcare professionals may change their mind as the task they have undertaken becomes clearer, and the emotional burden more apparent.(145) It is therefore important to establish what children and families consider priorities in their home life. Such priorities will influence how decisions are made which affect the child's health. While recognising the challenges that families face in providing care in the home environment, researchers have tended to focus on improving family education and training, rather than seeking alternative explanations or solutions to these issues.(113)

Evidence about how children, families, and professionals currently practice infection control for invasive devices in children at home is urgently needed. Increasing numbers of children with complex medical needs are living at home yet how families manage IPC in this environment remains poorly understood. Attempts to address device-related infection in the home have focused on education and training for families, but these efforts have demonstrated limited success. More work is required to understand how families carry out IPC measures, and the different influences on device care in this setting. Children with invasive devices have complex medical needs which impose their own demands on the family and which may influence how children, families and professionals respond to the demands of IPC. In section 1.4, I set the challenge of caring with an invasive device in the context of the broader literature on chronic illness and co-production of healthcare.

1.4 IPC in children at home: the theoretical framework

As I have demonstrated in section 1.3, addressing device-related infections in the community is a complex issue. While providing education and training for patients and family members can improve outcomes, the evidence from existing programmes suggests that such an approach will not result in the same reductions in device-related infections as have been seen in hospitals.(75,96,144-147) As I describe in section 1.2.4, strategies to address device-related infections have met with varying success when applied in different settings. The context in which strategies such as care-bundles are implemented may have as much to do with the success of these endeavours as the technical components which comprise the intervention.(149,150)

As more children with complex medical conditions are care for in the family home, the responsibilities that families take on is increasing. Understanding infection risks requires deep understanding of the challenges faced by families looking after children in the community. Such challenges are not confined to device-related infection but are part of the broader experience of caring for children with chronic illness. Children with invasive devices have such devices inserted because of underlying complex medical conditions which require highly specialised care to manage. Thus the care of the child with an invasive device requires families to care for the child with the illness in addition to the requirements of the device.

I recognise the need for an appropriate theoretical framework to advance the investigation of IPC in children living at home. While much of the purpose in this thesis is to give voice to, describe and characterise the influences on the topic rather than test hypotheses or develop new theory, it is important to be sensitive to the theoretical constructs likely to be valuable in drawing insight into this complex area. I draw on coproduction as a theoretical construct with potential value for understanding the complexity of managing IPC in a context where families and health professionals play important and interrelated roles.

1.4.1 Balancing the demands of managing chronic illness with maintaining IPC

Children have invasive devices inserted for a wide variety of different medical reasons. However, there are some common experiences in the care of the child with a chronic

illness which are also relevant to the child with an invasive device. Management of chronic illness requires tasks to be carried out which impose physical, cognitive, and emotional burdens on all parties. Efforts to reduce device-related infections take place alongside the demands of caring for a child with a chronic illness, where carers face multiple competing priorities in the care of the child. In this section, I review the impact that the care of the child with a chronic illness at home has on the child, their parents, and wider family.

The management of chronic illness requires a number of tasks which vary with each condition.(151) Some children require continuous attention while others may need brief periods of intervention.(152) In the case of children, much of this work devolves on family members – usually mothers who act as the primary caregivers.(153) Some children require highly skilled and technical nursing care which is provided by parents and other family members.(154-156) Care for some children can be physically demanding, as families have to carry the child or move heavy equipment.(156,157) Beyond the technical care that families provide, domestic tasks (washing, shopping, cleaning) must still be carried out.(158) Parents are exhausted by these care demands, losing sleep as they try to carry out all the care the child requires.(156,158,159)

Taking children to appointments with healthcare professionals or to receive therapies is time-consuming and disruptive to the family's everyday life.(160,161) Children with rare or complex medical conditions are often cared for in specialist hospitals which can be long distances away from the family home.(161,162) Some attendances are planned, but children with chronic illness are vulnerable to acute exacerbations of their condition, leading to emergency hospital admissions of uncertain duration.(163) Such admissions lead to significant disruption to everyday family life which impact on the child, parents, and wider families.(161,163,164) Families are split as the child is away from the home – parents must choose between staying with their child in hospital or staying with the rest of the family.(162) Healthcare visits, whether planned or emergency can be expensive as families pay for transport and food.(152)

The time required to care for a child with a chronic illness, coupled with unpredictable episodes of illness mean that parents struggle to balance employment with the care of the child. Parents may change jobs, reduce their hours, or give up work

completely.(152,159) Reduced employment opportunities, combined with the additional expenses of care mean that families face financial difficulties.(152,165)

Caring for a child with a chronic illness is a relentless and exhausting role for families.(158) Parents act as managers of their child's care.(153,158) Ensuring that these tasks are carried out in a timely and efficient manner carries a cognitive workload.(152) Medications must be ordered, collected from pharmacies, and administered at the correct time for children to receive the benefit of the treatment.(152) Families coordinate the ordering and delivery of equipment and feeds.(152) In addition to organising and managing the child's care, parents must also become experts in their child's illness, actively seeking out information to support the care of their child.(154,155,157,160) The management of childhood chronic illness takes place alongside the other family routines of everyday life.(166) Most children, even those with complex medical needs, still go to school, play with their friends, and take part in family activities.(103) Parents exist in a state of constant vigilance, continually monitoring the child for signs of illness, and adding to family anxiety(155,158,167) Children's actions are continually re-evaluated in the context of the illness, which can make seemingly innocuous events indicators of serious illness.(155) Families make decisions about their everyday lives in a bid to maintain some degree of normality for the child and other family members.(162,168) In some cases, the child's needs can be amalgamated into the everyday life of the family, for example by all eating the same meals or adhering to the same daily routine.(152,162) In other cases, families make complex decisions when prioritising the demands of the illness alongside the importance of maintaining "normal" family routines.(169,170) Balancing these often conflicting demands requires considerable skill and adds to the burden that families experience.(152,168,170)

In addition to managing the child's illness within the family and social networks, families also interact with the numerous professionals involved in the care of children with chronic illness. Families learn to navigate these complex networks of care providers to ensure that the child's needs are recognised and met.(154,156) (160) Some healthcare professionals may be unfamiliar with the child or their condition, leaving families in the position of information givers.(160) Outside the healthcare environment,

parents may be the only source of information for other carers, such as school-teachers.(171)

Children's social interactions are limited because of the restrictions imposed by the illness, or the therapies required to manage the condition.(162,172,173) The physical consequences of illness mean that children may not be able to join in normal play.(173,174) Medications must be taken at certain times, thus children are constrained by the timetable of their illness.(152) Everyday childhood events, such as sleepovers or playdates are curtailed as children need to be home by a certain time.(161,172) Frequent hospital admissions or healthcare appointments mean that children are absent from school, making it difficult to maintain friendships.(153,173,174)

The restrictions imposed by chronic illness limit children's participation in their family circle and wider community. Children may not be able to participate fully in cultural and religious festivals, particularly if these involving dietary changes or restrictions.(162,172) Travel is restricted by the need to have access to healthcare or the constraints of therapeutic equipment which is bulky and cumbersome to transport. Having a family holiday thus poses additional challenges. Children may also be unable to visit the family's country of origin, missing important links with their heritage and identity.(172) Such restrictions have consequences for relationships within the family.

Parents also find their social interactions are restricted by the demands of caring for a child with a chronic illness as care is time-consuming and has to be carried out at certain times.(154,161,162,167,172) Difficulties in accessing social spaces, such as cafes and playgrounds, mean that families' opportunities for social interaction are further limited.(157,175) The demands of providing care mean that parents change jobs, or sometimes stop work altogether, resulting in further disruption of their social networks.(152,162,165) The resultant loss of income further restricts families' activities.(157) Even when families do manage to spend time with other people, they may find that they have little in the way of shared experience to bond over.(157,158,173)

Families also suffer from the emotional impact of caring for a child with a chronic illness.(157,165,175,176) Parents worry that they are unable to care for the child

effectively (154,158), and are distressed by their inability to fully alleviate their child's symptoms. (167) In addition to the stress of caring for the child, families are saddened by the impact of the illness on the child and wider family.(157) Feelings of sadness and loss persist well beyond the shock of the initial diagnosis, magnified at anticipated life events (such as the first day at school) which emphasise the effect of the child's illness.(157,177) Unexpected health crises further add to these feelings of sorrow.(177) Parents have to cope with their own emotional distress, while addressing the emotional needs of the child and other family members.(151,164)

Family members may find they have little time to spend with one another away from care demands, affecting relationships between parents and with other children.(152,157,175) Siblings share many of the emotional burdens experienced by parents, and may also undertake caring activities (such as giving medications), or take on the indirect burden of domestic tasks instead of their parents. (151,152,178) The impact on everyday life is particularly significant: families may not have the resources to maintain these routines when a child is unexpectedly unwell, leaving siblings unable to attend school or other activities. (163,173) When siblings are able to attend school, the stress and anxiety of care can leave them unable to concentrate and their school performance can suffer.(178) The realisation that siblings are also affected as a result of the disruption to family life contributes to the feelings of guilt and sorrow that many parents experience.(177)

Thus children with invasive devices and their families face a number of challenges as a result of their underlying condition which will influence how they approach IPC in their everyday lives.

1.4.2 Co-production

Designing services which support families and professionals to care safely for a child with an invasive device at home requires an understanding of these different influences.(179) Families who care for children with complex needs carry out this care in the context of their existing family lives – the decisions they make around care are influenced by the needs and resources of the child, the wider family, and the community in which they live.(180,181) In order to fully appreciate how device-related infections

can be addressed in children living at home, an approach which considers the role of multiple partners in device-care is required.

The care of a child living with an invasive device at home could be considered a case where the *co-production* model is particularly apt. The term “co-production” was first used by Elinor Ostrom to describe how public services rely on the actions of both service providers and service users to be effective.(182) In its simplest form, co-production recognises that the recipients of public services are involved in both delivering **and** receiving services.(183) The term has since been used to describe the interaction between co-producers in a variety of public services, including healthcare.(184,185)

The role of patients and families in healthcare is changing. There is a growing realisation that the existing ways of delivering services are neither efficient nor effective for the challenges they are supposed to address.(186) Modern healthcare systems have been very successful in dealing with acute threats to health, but may not be as well suited to managing complex and long-term health conditions.(186) Long-term health conditions have a significant effect on the quality of life of patients; they also have considerable effects on patients’ families, friends, and wider communities.(185) Financial pressures are likely to worsen in the coming years as public service budgets are cut further (187), and provide an additional impetus for services to encourage families to contribute more to the care of the patient in their own home. The engagement of children and families is a recognition of how care is already being delivered, and will be delivered in the future.

Government policies encourage families to take on more of the care of patients with complex health needs in the community.(188) Long-term health conditions have a significant effect on the quality of life of patients; they also have considerable effects on patients’ families, friends, and wider communities.(185) Healthcare is no longer delivered primarily in designated healthcare settings, but increasingly complex care is being provided in the community and in people’s own homes. Families are responsible for delivering much of the day-to-day care of the child with an invasive device, supported by formal healthcare services. Families respond to dilemmas in everyday life via a complex network of social interactions within their community.(189) Such

interactions can result in “real life” solutions to the everyday challenges of caring for a child with an invasive device, therefore service models which engage patients and families may be better suited to addressing the needs of patients with complex health needs at home. Patients and their families are therefore both recipients **and** producers of healthcare alongside healthcare professionals.

The public sector is increasingly interested in service delivery models that use co-production, to the extent that commissioners have explicitly encouraged providers to incorporate a “co-production model” into their bids.(186) Recent years have seen the use of this approach to devise new ways of delivering youth justice, supporting people with learning disabilities to live in their own homes, and supporting the self-management of long-term conditions such as diabetes and chronic pain.(183,184) This approach means moving away from seeing service users as merely clients with a list of problems that need to be addressed by the service provider, and instead recognises that the users of services also contribute to the success of that service.

Although the term “co-production” is relatively new, the interaction described between service provider and service user to produce a desired outcome is a long-standing one. Ostrom’s original work described an existing process whereby formal providers worked with service users who were not recognised providers. In her study of police function, members of the community (outside the formal structure) provided vital information and support for the police officers (inside) to carry out their work and maintain a safe community. This was not a new intervention or project, but an exploration of how an existing service was produced.(182,190) A similar situation is seen in healthcare. Throughout the history of medicine, treatments have depended on both physician and patient working together to co-produce health. The contribution of patients is essential to ensure that symptoms are elucidated, diagnoses established, and treatments carried out. Patients make the decision to present to healthcare services when they feel in need of medical attention; they select which pieces of information they share with the healthcare provider, and decide whether or not to follow treatment advice. Thus co-production is not a new method of delivering healthcare. Rather, the study of co-production is intended to result in the development of services which are more closely aligned with what patients and their families think of as “good” healthcare, and provides

a more rounded understanding of how public services in the future can be developed.(184)

The co-production model has been used to describe interactions between co-producers at an individual level, as well as interactions involving third sector organisations and citizen groups.(191) Notwithstanding these variations, the key point of Ostrom's original definition is present in all subsequent discussions on co-production: services are produced through the joint efforts of formal service providers **and** those who are not recognised as providers by the existing system. The care of children with invasive devices is shared between the professionals who are formally associated with the service child and their family who are directly affected by the care that results.(190)

1.5 Conclusions

Addressing device-related infection in children living at home is a complex issue which remains poorly understood. Efforts to support patient safety outside of hospital cannot simply be transferred from one environment to another without first addressing these influences in the community. Inhibitory, as well as supportive factors to parent and family involvement should also be considered. The child, family, formal services and other carers all have an important role to play in the maintenance of sterility, and the management of device-related infections, and all should be considered partners in pursuit of a shared goal. In order to develop meaningful guidance for families in the future, it is important to identify where participants believe the risks of infection arise: to explore how the various parties involved (children, families, healthcare professionals, and formal carers) who share responsibility for the care of an invasive device understand and assess infection risks, the actions and strategies they use to minimise these risks, and the challenges they face; and to characterise how best the efforts of these partners can be coordinated and supported to optimise infection control. Such work would support health professionals to work in partnership with families to manage infection risks in invasive devices, and enable the empowerment of children and families.(186)

Infection control lessons learnt from intensive care or adult practice cannot simply be transferred to care of children in their own home where decisions are made by children,

families, and professionals. Nor can the research be confined to a single group of participants. The different contributors to the child's care will have varying interests at stake, which will influence how the same phenomenon is viewed.(124) While clinicians are supportive of involving children and families in decision-making, this support depends on the type of decision and the context in which it is made. Families' decisions regarding infection control practices may not be fully understood by clinicians, and thus not supported. In order to evaluate IPC practices in children with invasive devices, it is necessary to explore the experiences of children, families, and professionals.

In this thesis, I aim to explore how infections risks associated with the device are understood, assessed, and responded to by children, families, and professionals. I will examine what strategies are used to minimise these risks, and what challenges are faced in implementation. I will reflect on the aspirations of co-production in relation to the realities of managing IPC in children living with invasive devices. I will conclude by proposing ways in which children, families and professionals can best be supported to work together to optimise infection control.

2 Study Design

2.1 Introduction

This thesis is concerned with the challenges that children, families, and professionals face when carrying out device care in the child's own home and wider community. In this chapter, I describe the study design and consider how the research aims were developed with the involvement of patient and professional groups alongside my clinical experience. I outline the methodological approach used, before describing in detail the process of recruitment and data collection with children, families and professionals. I go on to explain how the data were analysed, reflecting on my role as a researcher in interpreting the data, and conclude with an overview of the ethics and research governance processes.

My review of the literature, reported in Chapter 1, demonstrated that there was little existing empirical evidence in this area. As this was a relatively unexplored field, I decided that a qualitative methodological approach would be appropriate. I wanted to study how the different participants experienced device care, and how IPC practices are managed in the child's own home. Qualitative methodologies are ideally suited for exploring topics about which little is known, and to elicit the views and experiences of participants.

The aims of the research are to:

- Explore the views of children, families, and professionals as to which factors place children living at home at risk of device-related infection.
- Explore how children, families, and professionals understand and assess infection risks associated with an invasive device
- Examine the actions and strategies that children, families, and professionals use to minimise the risks of device-related infection, and what challenges are faced in implementing these strategies
- Propose how best the efforts of these partners can be coordinated and supported in order to optimise infection control.

2.2 Patient, public and professional involvement in developing the research questions

Some background is helpful in explaining my interest in this area. I am a paediatrician in training. Because of the way medical training is structured in this specialty, I have mainly seen children in the hospital setting, while looking after children who are acutely unwell, or in out-patient clinics that take place in clinical environments. Very little of my work relates to children's everyday lives away from healthcare environments.

Working on an oncology unit as a junior doctor, I realised how little I knew about the interaction between children's medical conditions and their everyday lives away from the hospital. From conversations with children and their parents on the ward, it became evident that device care at home was a particular concern for children and their families.

After discussions with colleagues, I undertook a scoping literature review to examine what was already known about the experiences of children with invasive devices living at home, and their families. I was particularly interested in infection control, as I had cared for children who had become very unwell as a result of central line-infections. It was clear from the literature that very little was available that offered insight into the challenges faced by families in effective IPC for a child with an invasive device living at home, and that empirical research was needed to fill this gap. Before defining my questions, I felt it was important to have patient, public and professional involvement.

2.2.1 Discussions with representative from a parent group

From the experiences I had of talking to families on the oncology ward, I had already begun to get a sense of the issues that families faced. To frame my research questions with patient and public involvement, I began by meeting with the parent of a child who had had a central line at home. Janet is the mother of a child who was treated for cancer several years ago. Her daughter had been off treatment for several years, and Janet now has a role as a parent representative within the children's oncology service. Janet established a website that provides support and information for the parents of children with cancer in the East Midlands area. As well as her own experiences, she was in contact with a large number of families of children with cancer in the region. I made

contact with Janet via the website, and invited her to discuss how I could best approach the research question.

Janet felt that her personal experience, and that of other parents, confirmed the need for improved information on central-line care, and a move towards seeing parents as partners in device-care.

Some of the themes I took away from our meeting were:

- Families not being given the opportunity to participate in their child's care as much as they would want to, particularly with regards to central line care.
- Concerns about professionals caring for and using the device
- The restrictions that having an invasive device placed on children and families' daily life.

As the research progressed, Janet and her group were involved in discussions about recruitment strategy and gave feedback on the design of participant information leaflets.

I recognise that a meeting with one parent has limitations and is unlikely to be representative of the experiences of a wider group of families. However, this meeting confirmed that device-related care was an issue for families and children. It also suggested that having an invasive device placed significant restrictions on families' everyday lives, and that families had to make substantial changes in their lives in order to adapt to the care of the device. It was an indication that families did not always feel they were treated as partners in their child's care.

2.2.2 Discussions with clinical staff

Clinical staff were also involved in initial discussions when planning the study, and in particular, the approach towards recruitment. My experience of working with the paediatric oncology team at Leicester Royal Infirmary suggested to me that the professionals felt that the relationship they had with patients and their families was very precious to them. They would not be willing to imperil that by being associated with a study that families would not support, or that could cause them harm or distress.

Therefore, in order to ensure the support of professionals, they had to believe that the study was acceptable to families. The response I received from the children's community nursing team after I contacted them reassured me that this was the correct approach to take. I discussed the study with the community nurse team leader initially by e-mail at the planning stages, and then again in person as the protocol was finalised. This was one of the shortest conversations I had about the project. The team leader felt the approach to recruitment was uncomplicated and made appropriate use of her team's expertise and knowledge of the families they cared for.

2.3 Methodological approach

Qualitative methodology is concerned with investigating complex phenomena in the real world setting.(192-195) Such an approach is ideally suited to answering my research questions as I am investigating the challenges of carrying out device care in a real world setting. A research approach which explores how device care is carried out in the naturalistic environment of the child's home and wider community enables the identification of real world challenges that families and professionals face, as well as the tactics used to overcome these challenges.(196,197)

The care of the child with an invasive device at home is complex and involves numerous different partners working together. Qualitative research is also well-suited to exploring the complexity of interaction between different partners who may have different beliefs and priorities in the care of the child.(192,197) By exploring the multiple influences on device care, qualitative research can explore how guidelines on IPC are put into practice in the child's own home and wider community.(197,198)

Qualitative research is particularly useful where a subject area is under-researched. My review of the literature demonstrated that little is known about how infection control is maintained outside of acute healthcare settings, or the roles that different partners play in reducing device-related infections. Qualitative research can explore how device care is experienced by children, families, and professionals, and provides a framework for further research.(192,193) In addition, qualitative research can uncover issues that researchers had not previously considered as important factors.(198) Such issues can then form the basis of further empirical research, enhancing the understanding of the

subject. Thus qualitative research is an appropriate methodological approach to investigate the complexity of how families and professionals implement guidance on IPC in the community.(196)

2.3.1 Study Design

A qualitative design was used, involving interviews supplemented by field notes, with twenty families where the child had an invasive device. Semi-structured interviews were conducted with twenty healthcare professionals who support the care of children with invasive devices in the community. I recognise that the care of a child with an invasive device in the community is a complex interaction between families, children, and professionals. Furthermore, children do not exist in isolation: rather they are part of a societal structure which acts as a gatekeeper between children and the health-service, moderating the care that children receive.(199) Therefore it was important to hear the voices of children, families, and professionals in this study.

Two groups of participants were recruited to this study. Children with invasive devices and their families were the first group of participants recruited. Data were collected via semi-structured interviews. Field notes and observations were recorded to contextualise the interview data. As the interviews progressed, groups of professionals involved in supporting children with invasive devices and their families were identified. Members from these professions were invited to take part in semi-structured interviews. After the initial interviews with children and families, recruitment of both groups took place concurrently. Twenty children and families, and twenty professionals were recruited.

2.3.2 Data collection

Data were collected by semi-structured interviews which focused on experiences of living with, and caring for a child with an invasive device. This method was ideally suited for the exploration of ideas as I could explore participants' views and experiences in depth.(194,200) In this way, the meaning of particular phenomena can be co-created between the participant and researcher.(200) More specifically, semi-structured interviews can be used to elicit "script knowledge": the understanding of situations and experiences constructed over time, rather than a single incident.(201) This was

particularly useful in this study as it allowed the exploration of families' routines in their care of the device.

The semi-structured interviews were organised around particular areas of interest (200), based on the review of the literature. Separate prompt guides were developed for children, families, and professionals to ensure that the interview covered key areas of interest. (See Appendix B). The prompt guides were developed following my literature review and initial meeting with the patient representative, and were designed to address the areas of interest outlined in the research questions. In the event, interviews were led primarily by the participant and the prompt guide served as an aide-memoire to stimulate dialogue. I found that attempts to steer the interviews too closely were counter-productive. As well as providing useful contextual information, allowing the participant to lead the interview led to the exploration of new themes which arose unprompted.(200) Although not part of my original focus, these stories later formed an important part of my analysis. An iterative approach was used, where information collected during previous encounters was used to inform areas to explore in subsequent interviews.

2.4 Children and Families

A list of inclusion and exclusion criteria for child and family participants was drawn up to ensure a sample that would best meet the research questions. These criteria are detailed in in *Table 2.4*.

Table 2.4. Inclusion criteria for children and families

Inclusion criteria	Exclusion criteria
<p>Child aged 4 – 12 years with an invasive device in place for at least 3 months</p> <p>Living in the community with family or carers</p> <p>Male or female</p> <p>From a range of ethnic and socio-economic backgrounds</p> <p>With a variety of medical conditions requiring use of an invasive devices</p> <p>Written consent given by parent or guardian with parental responsibility on their behalf, and on behalf of the child</p>	<p>Child did not have an invasive device in place at time of recruitment</p> <p>The child normally lived away from the family unit (e.g. in long-term hospital or residential care) where the care of the device was exclusively by healthcare professionals</p> <p>The parent or guardian with parental responsibility had not given written consent, or had withdrawn their consent at any time.</p> <p>I had ongoing professional contact with the child or family (discussed further in section 2.4.4)</p>

2.4.1 Sampling Framework

A purposive sampling framework was devised with the aim of gaining a wide range of experiences where the child lived at home with an invasive device. (198,200,202) I designed a sampling framework to enable me to answer the research questions set out in section 2.1. The criteria for inclusion in the study were families with a child with an invasive device living at home and in an age-range where they would be expected to interact more frequently with the wider community, indicated by school attendance. Because the focus of this thesis was on infection control, specific devices were considered eligible for inclusion: tracheostomies, gastrostomies, central-lines and Portacaths are all devices which carry a risk of infection, as outlined in **table 1.2.**, which can be minimised by attention to infection prevention and control practices. (Other devices considered eligible included peritoneal dialysis catheters and indwelling urinary catheters. In the event, no children with these devices were recruited.)

This thesis deals with care of the invasive device rather than a specific disease entity, thus children with a range of diagnoses (and some with no diagnosis at all) were eligible for inclusion. Other factors which may have an impact on the care of the child (such as socioeconomic status and family structure) did not form part of the sampling framework.

The age range (ages 4 – 12 years) of the children selected was partly purposive, and partly pragmatic. I was interested in the role that different care providers played in the care of the child with an invasive device. By the age of four, most children regularly spend some time away from the family unit, for example at nursery or school.(203) Children with invasive devices are therefore in contact with carers outside the home, and away from their family. Setting a lower age limit of four years allowed me to explore the complex interactions between children, families, and professionals both in the home, and in other community settings.

Most researchers agree that interviews can be successfully conducted with children aged four years and above.(204) I had previous experience of conducting research interviews with children aged between five and seven, and felt confident that I would be able to develop these skills further. The upper age limit was set because I was interested in the role that children and families played in the care of the device. Children older than twelve years of age are more likely to see health care as their responsibility, rather than that of their parents (172), thus the nature of the discussions could have been very different if older children and young people were included.

I was keen that the families in this study had some time to gain experience of living with the device, therefore I stipulated that the device had to be in place for at least three months before the family could take part. This time period also meant that the family had some time to become accustomed to the device. As a result of my professional experiences as a paediatric registrar, I was aware that device insertion could take place at a time when the child was seriously unwell or had just received a new diagnosis. Mandating that the device had to have been inserted at least three months previously gave the child and family some time to recover from the initial shock of device insertion. Ensuring that the device was still in place at the time of the interview helped facilitate data collection as I could directly observe the care of the device in some cases.

As the focus of this study was on the care of children with invasive devices in the community, children had to be living at home rather than in long-term hospital or residential care. I recognise that within formal healthcare settings the technical care of the child can be shared between family members and professional carers. However, the balance of responsibilities and frameworks for preventing infection are necessarily different in such cases, thus children cared for in hospitals or residential care were excluded.

Diagnosis or medical condition were not included in the inclusion criteria. This was for three reasons: first, I was primarily interested in the impact that the device had on the child and family, rather than the underlying medical condition. Second, reviewing the literature, I had established that children with a wide variety of different conditions used invasive devices, and it would be difficult to form a comprehensive list of diagnoses to include. Third, I was aware that some children who required invasive devices did not have a formal diagnosis, therefore making a diagnosis a condition of entry into the study could have excluded some families.

I aimed to include all children who met the inclusion criteria in this study. However some children did not have the verbal skills to fully participate in interviews. It was left to the parents to decide if their child could take part in the interview or not.

2.4.2 Initial approach to recruiting children and families

The initial recruitment strategy relied on the recruitment of families via their clinical teams, using a purposive sampling strategy to seek a maximally diverse sample of participants.(198,200) This proved challenging in practice, with initial difficulties in recruitment. In the sections that follow, I explain how the recruitment strategy had to be modified in response to pragmatic and logistical challenges, and learning from initial interviews.

I was aware that children who were potential participants in this study had complex medical needs and that their health could deteriorate very quickly. Often families are struggling to come to terms with changes in circumstance. Under these circumstances, I did not want to place any additional burden on the families by asking them to participate in a study when they were already struggling.

The approach to recruitment was discussed at an early stage with different professionals working in children's oncology. These professionals were: a ward sister; a consultant in paediatric oncology; and a play specialist based on the oncology ward. I chose these professionals because they were a group with whom I already had a working relationship. I knew they had a close relationship with their patients too. In addition, I felt that the range of opinions would ensure that all dimensions of the patients concerns were represented (some patients might only disclose information to their play specialist rather than their medical or nursing team). Furthermore, I knew that they were staunch advocates for their patients and families. They would not endorse anything they felt would be detrimental to the care of the patient, including to their emotional wellbeing.

My initial approach was therefore to minimise any additional pressure on families by asking healthcare professionals to screen which families they thought would be suitable to approach, e.g. if the child's health was relatively stable and they were not experiencing acute deterioration. This meant that families who were felt to be struggling by their clinical team would not be approached.

Children and families were identified by a healthcare professional who was involved in the care of their child. Three NHS hospital trusts were approached and each agreed to recruit families from specialist paediatric clinics. An NHS trust providing specialist community nursing services for children also agreed to approach families with information about the study. These four trusts were selected as I had existing professional relationships with clinicians who cared for children with invasive devices at these trusts.

As described above, families were only invited to participate if their clinical team felt that it was appropriate to do so. Families were given an information pack about the study by a healthcare professional directly involved in their care. Posters outlining the purpose of the study, and inviting families to discuss the study with their clinical team were also displayed in waiting areas. I attended out-patient clinics and day care units so that I was available to discuss the study with families if they expressed interest.

If families were interested in taking part, and wanted further information about the study, they were then asked to complete and return a reply slip so that I could contact

them to discuss the study in more detail. Once potential participants made contact, I was able to go through the study and ensure that the inclusion/exclusion criteria were met. We agreed a mutually convenient date and time for data collection, and I asked permission to contact the family a few days beforehand to confirm that the appointment could go ahead. Telephone contact meant that the family could re-arrange if the necessary (e.g. if the child became unwell).

2.4.3 Challenges to recruitment using the initial strategy

The initial approach to recruitment was not effective and had to be modified. Recruitment of children and families via the methods outlined in section 2.4.2 was very slow: after six months, only one family had taken part in the study. After discussing the approach to recruitment with front-line healthcare professionals and reflecting on my approach to this point, I identified a number of barriers to recruitment.

First, the recruitment approach was dependent on healthcare professionals promoting the study to families. This raised two challenges: first, professionals had to remember to raise the study with families, and to find time to do this in a busy clinic environment; second, families had to be willing and able to listen to the study information. To address this problem, I made repeated visits to the recruiting Trusts to raise awareness of the study to front-line staff by talking to staff informally in coffee-rooms and staff handovers. Although I had formally presented the study during educational meetings at the participating Trusts, these meetings had not included all staff who had direct patient contact. Visiting the sites gave me the chance to talk to staff directly, and to answer their questions about the study.

Second, families who had frequent contact with their clinical teams were likely to have competing priorities for their time and energy, especially during clinic visits. Families visited their healthcare professional to receive medical care and support - research participation might not be a priority for families or professionals during these visits. In my initial approach, the onus was on the families to complete and return the reply slips once they had returned home. Even if the family were interested and we had discussed the study at length, I was unable to contact them until the reply slip had been returned. Front-line staff felt that potential participants were unlikely to take the initiative to

approach researchers, even if they were intending to consent to the study. Healthcare professionals felt that families were generally supportive of research, but that research participation was unlikely to be their priority once they were home.

Third, as children progressed through treatment, and their condition stabilised, families had less frequent contact with their clinical teams. My initial recruitment strategy meant that as families become more used to the device, there were fewer opportunities for the clinical team to discuss the study with them.

2.4.4 Modification of the initial recruitment approach: changes to the recruitment strategy

A number of changes were made to the recruitment strategy in order to overcome the identified barriers. In particular, I amended the recruitment approach so that families could be engaged outside of the clinical environment and without direct approach by a member of the clinical team caring for the child. Posters introducing the study had already been placed on wards and clinic areas – these were amended to include my contact details (telephone and email) so that families could contact me directly if they wished. A webpage was created for the study with links to the participant information leaflet, and a contact form so that interested participants could leave their details. This webpage was shared through open social media, parent support groups, websites, and parent magazines. Through the support of personal contacts, the study webpage was shared through closed parent groups on social media.

I continued to attend outpatient clinics and encouraged professionals to discuss the study with their patients where suitable. Professionals suggested that families could be asked for their contact details (such as a telephone number and a suitable time to call) so that I could contact the family after a few days. This gave families a chance to think about the study, and meant that the burden of making contact was taken from the families. To ensure that families did not feel under pressure, this was only for families who had expressed interest in the study to their clinician and where we had discussed the study during their clinic visit. I made it clear to families at every stage that there was no obligation to consent to the study.

Originally, I had only intended to recruit children with tunnelled central lines as CLABSI reduction had been the focus of much research. As the challenges to

recruitment became more apparent, the inclusion criteria were amended to include children with a wider range of invasive devices. As a result of work recently undertaken by a local parent group, clinical teams became more aware of the restrictions that tunnelled central lines placed on families.(205) More children were receiving totally-implanted central-venous access devices (Portacaths) than in previous years, and fewer children had tunnelled central lines inserted. I reviewed the literature, and established that children with other invasive devices were at risk of developing healthcare-associated infections in the community. Children with multiple invasive devices were at increased risk of infections (79), and many of the challenges faced by children with central lines were also experienced by children with other invasive devices.(102-105) The study protocol was therefore amended to include children with all invasive devices which were associated with infection.

In order for these changes to take place, a major amendment to the study protocol was submitted for NHS research ethics committee approval. The changes altered the inclusion criteria so that children with invasive devices other than central lines could be included in the study. The recruitment process was amended so to allow me to promote the study in the public domain. I specified that a link to the webpage would be shared on social media, and that the study would be advertised to family support groups via websites, mailing lists, and other communications such as magazines. The amendment was granted in August 2014.

2.4.5 Data collection with children and families

Families expressing interest in participating were invited to be interviewed. I made contact with parents via telephone or email according to their preference, initially to confirm that they had read the participant information and were happy to proceed. I then continued discussions to arrange time and place for the interview that the family were happy with. In practice, the parent involved in these discussions became the participant. The location of the interviews was selected by the family: all interviews bar one took place in the family home. (One interview took place during a planned hospital admission at the family's request as this was more convenient for them). The data from the interviews were supplemented by brief periods of observation during my time with the family, which were recorded as written, reflective field notes. Visits to the family

varied in duration from 40 minutes to over three hours, although most visits lasted around 90 minutes. Children who took part in the study were interviewed during the same visit.

It was important that a rapport was established quickly with the families as I had limited time in the home and wished to explore their personal experiences.(200) As I had made contact with the families during the recruitment stage, I felt that we had an existing relationship which helped establish a rapport early on in the interview. In addition, for most families, I had been introduced by a clinician whom they knew well or by a peer family. Thus there was an existing relationship before the interview began. Interviews with parents were structured so that we began by reviewing the child's medical history and reason for device insertion. I felt that this structure helped to build rapport with the parents as families were accustomed to responding to similar questions.

My intention had been to carry out parent interviews separately from children. In practice, this only happened when the child was not present in the family home (for example, if the child was at school). I reflect on the implications of parents and children both being present during the interview later on in this section.

Interviews with parents were often interrupted by everyday activities, such as telephone calls and visitors. I initially found these interruptions frustrating, interrupting the flow of the interview and disturbing the rapport that I was establishing with the families. I soon realised that these interruptions provided further context to family life with an invasive device, such as telephone calls about a child's care, arranging appointments, or organising deliveries of feeds or medications. Some families had only been able to arrange to see me because they were also having to stay in to wait for deliveries or visits by healthcare professionals. Reflections on these episodes were recorded in my field notes. Interviews were digitally recorded, and transcribed verbatim by professional transcribers for further analysis.

Data collection with children required a slightly different approach. I take the position that children are experts in their own lives, and are competent to share their experiences. Positioning children as the expert voice is important for several reasons. First, acknowledging that the views of children are valid and therefore should be included in

research enhances the data available. Second, it is inevitable that power imbalances exist in the research relationship despite efforts to minimise them: recognising children as experts goes some way to ameliorating this imbalance.(199) Third, there is growing evidence that children make an important contribution to maintaining their health in chronic illness: a failure to recognise children as active agents in their care would miss this contribution.(134)

Researchers have tended to see children as extensions of adults, rather than experts of their own lives, views, and experiences.(206,207) They have struggled to engage children in conventional data collection methods, such as formal interviews.(207) As a result, younger children in particular have been seen as having little to contribute.(208) Instead, experiences of significant adults (such as parents, and teachers) were sought regarding their views of the child's perspective.(209,210) Research has therefore taken place *on* children, rather than *with* children. The experience of other researchers has demonstrated that young children, previously ignored as key informants in research, can make valuable contributions.(208,211,212) However, authentic and meaningful participation depends on using the appropriate methodology and data collection.

The interviews focused on the child's experiences of living with an invasive device, and used a narrative approach to elicit the child's daily routine. In my interviews with children, I used a combination of drawings, role-play, and worksheets to create a non-threatening environment where the child could describe their feelings and experiences.(204,213) Previous researchers have used drawings or play to support interviews, and role play with soft toys can also be used to conduct interviews.(214,215) Art-based techniques have been used by a number of researchers, both to facilitate other means of data collection (e.g. interviews) or as a source of data for analysis in themselves.(216,217) Using tasks such as drawing can help focus the discussion between researcher and participant, and may improve the quality of the interaction between the two.(218) Children are familiar with drawing as an activity, and are used to using this as a means of elaborating narrative.(206,218) Drawing has also been used successfully to explore complex concepts surrounding the issue of "care", where there are task-based and emotional ideas to be discussed.(206)

I offered children offered crayons and paper at the beginning of the interview. If the child asked for further directions (“what should I draw?”), I then suggested that they drew a picture of themselves or of their family. A soft-bodied doll (“Jo” – pictured in Appendix C) accompanied me to each interview: I had modified the doll so that it appeared to have a central line in place. I also devised two structured worksheets that were available for children to complete. One worksheet comprised an image of the modified doll, Jo, with thought clouds. Children were asked how they thought Jo felt about the device, and to complete the thought clouds. The second worksheet asked the children to complete the tasks associated with the device in the daytime and in the night-time. The worksheets were designed after review of materials currently being used in schools. (Examples of the materials produced during child interviews are available in appendix C)

Whether or not parents should be present during the interviews with children was an important consideration. The presence of parents is part of the context of the interview, and therefore can impact on the conduct of the interview and the interaction between child and researcher.(219) In some cases, this can be supportive: parents can act as interpreters of information, and support their children in making sense of the world.(220) Interviews conducted in the presence of parents can lead to more detailed responses from the child, and provides context to interpret the responses given by the child.(219) I was concerned that the presence of parents could restrict the child’s responses during the interview. Children are accustomed to having their views overlooked even when directly related to their own health (134), and they may expect researchers to be more interested in adults’ views rather than their own.(219) Where parents are supportive of their child’s participation, they may still influence the interview to meet their own agenda, or can try to help the researcher by prompting their child’s responses and interpreting their answers.(219) Despite this, some evidence from the literature suggests that children are prepared to challenge their parents’ and their interpretation of the child’s responses.(221) This is particularly true where the parent supports the child by exploring, rather than directing their responses.(219)

The presence of parents during the child interview was left up to the parent and child to determine. In practice, most interviews with children took place in a family space (such

as the kitchen) while the parent(s) were carrying out household tasks. Children frequently interspersed their own thoughts and reflections into the parent interviews, for example by asking for clarification of events. Where children were interviewed separately from their parents, the interviews were interrupted by the need to care for the child. Thus parent and child interviews were often intertwined. The interaction between parent and child helped to clarify the child's responses, and added to the richness of the data.

Interviews were digitally recorded and transcribed verbatim. All identifiable details (such as names and locations) were removed during transcription.

For each family included in the study, I requested permission to make field notes about aspects of device care that I observed during my time with them. I was able to make detailed observations about the care of the device, and the impact that device care had on family life. I observed: interactions between children, families, and professionals in the family home; device use by families and professionals; as well as observing how children interacted with the device in their everyday activities, such as play. These field notes contextualised and helped deepen my insight into the practical and routine challenges faced by children, as well as helping to identify areas of infection risk. To avoid unnecessary intrusion, I wrote up field notes away from the family home, as soon as possible after the interviews were concluded, based on recall and materials produced during the interviews.(222)

2.4.6 Ethical Considerations

I excluded families with whom I had ongoing professional contact with the child or family through my work as a paediatric registrar. Due to the nature of my work, there could have been circumstances where I had clinical responsibility for the child, for example, in an emergency. There was a potential conflict of interest here as I could be interviewing families about their experiences of care, and providing care to their child in my professional capacity. Discussion with parent representatives indicated that this level of contact was acceptable to them and that they did not consider this to be a conflict of interest.

Preserving the anonymity of the participants was key to ensuring that they felt able to speak freely about their experiences.(200) My work meant that I was aware that some children had very rare medical conditions which could make them identifiable even though the data were anonymised. It is for this reason that I have provided only minimal details about participants.

It was important that participants were aware that they could stop the interview or withdraw from the study at any time. I was particularly concerned that participants might experience emotional distress as a result of taking part in the research.(200) Some parents did find the interview distressing, particularly when they were talking about their child's illness. When this happened, I would suggest to the participant that the interview pause at this point. This allowed the parent to continue the interview if they wished. I did stop one interview despite the parent's initial statement that he wanted to continue. I initially asked the parent if he wanted the interview to stop ("Do you want to stop, or are you OK?"), and was assured that he wanted to continue. However, I was concerned that the parent's body language did not correspond and that he still looked distressed. I re-phrased the statement as "I'm going to stop now, is that OK?" and he nodded. Simply relying on verbal consent was insufficient to ensure that he wanted to continue, and I felt very uncomfortable pursuing the interview. In this case, and in others where families became distressed, I discussed what support the families had available and offered to raise the issues with their clinical team. However, all the participants felt that their clinicians were aware of the issues. In some cases, parents expressed that they had found the experience of discussing traumatic experiences with someone outside the clinical team as positive.

2.4.7 Specific ethical considerations in research with children

At the same time as recognising children's right to be included in research (211), I was concerned to ensure that individual children were not coerced into participation.(223) One possible reason for the relative exclusion of children from research is the desire of adults to protect children from exploitation in the name of research.(224) In this respect, research with children is thus no different from research with other marginalised or disempowered groups who also risk being exploited for the researchers' benefit.(224) However, I felt that I had to balance these concerns against the risks of excluding

children from participating in research. Participation in research may be empowering for some children, allowing them time to talk and express their views. Others are driven by altruistic motivation, particularly where the research may be of benefit to others in similar situations.(225) Other, less benign motivations exist, and it is important to be aware of these. Children may not be aware that they can refuse a suggestion made by an adult, or feel uncomfortable doing so. They may also wish to avoid causing distress to the researcher by their refusal to participate, or be persuaded by the views of other adults that research participation is a “good thing” to do.(223) I felt that understanding the potential for coercion allowed me to recognise the importance of the power relationship between adult-researcher and child-participant. Choosing an appropriate methodology and data collection technique meant that I could minimise the power imbalance. As a result, I felt that I ensured that children’s voices were heard in my research, while recognising the concerns about exploitation.(224)

Power imbalances exist in the relationship between participant and researcher even when both are adults. This imbalance is enhanced when the relationship is between child-participant and adult-researcher.(224) Adults can act to limit children’s engagement in research, even when they are enthusiastic about the research itself, thus affecting the child’s participation at various stages during the research process. As gatekeepers for children’s involvement in research, adults can determine which children they think are suitable candidates for participation.(226) During data collection, adult researchers and non-researchers may seek to protect children from distress by moderating their responses, but also limiting their participation.(224) The persistence of this imbalance affects the freedom of children to give assent or to withdraw from research, and may affect the responses they give.(224) Researchers face two main challenges: first, seeking to protect the child at the same time as acknowledging the impact of this protectionist role on the research.(223) Second, recognising that while adults act as gatekeepers this may limit the diversity of the children’s voices. As a consequence, there are difficulties in seeking to capture multiple realities in childhood research and recognising that childhood is not a homogenous experience.(226) Some children did not take part in the research at the discretion of their parents. While the reasons given were that the parents did not think that the child was able to contribute to the research, a number of children were excluded as a result. Where children did take

part in interviews, I was aware of the interaction between child and parent. I did not observe any overt instances where children's contributions were moderated by intervention of a parent; indeed, there were several instances where children directly contradicted their parent's assertions. However, I have no way of knowing if the presence of the parent did affect the children's responses; I can only report that I looked for signs of parental influence and did not find any.

Some researchers have suggested seeking formal consent from children rather than from their parents. In order for consent to be valid, it must be voluntary; sufficient information must be provided to the child in order for them to understand the research; and the child must have capacity to make a decision.(223,224) This has potential to further exclude groups of children from research if they are deemed (e.g. by age or by development) to incompetent to consent. In addition, reliance on formal consent processes may give false reassurance to researchers that the child has given informed and valid consent.(216)

Although children's assent should be sought throughout the research, others have encountered difficulties when putting this into practice.(199) Assent is an interactional process, based on the provision of adequate and appropriate information.(223) Part of the process of gaining informed assent to the research process is the provision of information to participants, including children.(226) Assent is formed on the basis that children will be able to refuse to participate, as well as being able to agree.(223) Experiences of researchers suggest that a child's refusal to participate in research is often unclearly expressed.(226) Power imbalances in the relationship restrict the child's freedom to refuse their assent to participate. Paying close attention to non-verbal and other cues from the child may give a clearer indication of their willingness to participate than a reliance on verbal agreement.(216,223,226)

Children with intellectual disability were approached to take part in the study if their parents gave consent – inclusion was guided by their parents who acted as gatekeepers and gave their assessment of their child's capacity to assent to the research.(227) This may have led to the exclusion of some children whose parents did not feel them to be competent or who were unable to contribute to a verbal interview.(224) While recognising that children with intellectual disability have a right to participate in

research, I am conscious that the data collection method would have excluded some children.(227) When parents did give consent for their child to take part, I sought to confirm this with the child, both verbally and through their body language as described above. All interviews took place in the presence of the child's parent and in some cases, the parent acted as interpreter of the child's responses. While this may have affected the responses I observed, the experience of other researchers working with non-verbal children suggests that they will contradict and challenge their parents in this situation.(221) I am aware that children with intellectual disability are particularly vulnerable. For this reason, all children were interviewed in the presence of their parent – no concerns were raised about child's safety or wellbeing in the information they disclosed.(228)

2.4.8 Information and consent processes

Families who were invited to take part by their clinical team received an information pack containing: a letter of invitation to participate; a parent's information leaflet; and an age-appropriate child's information leaflet. The documents contained information about the nature and purpose of the study, the contribution of participants, and the potential risks and benefits to participants. Families who heard about the study via advertising on social media or parents' groups received the same information via the study webpage or by email.

Families were offered time to consider the study, and to have a telephone conversation to discuss any queries or concerns. It was made clear throughout these conversations that discussions about the study did not commit families in any way to participating, that their participation was voluntary, and that they were free to withdraw at any time without impacting on the care of their child. It was also made clear that the clinical team looking after the child would not know if they had taken part or not.

Parents were asked to complete a written consent form for their own participation in the study. I went through the consent form with parents, and the forms were signed in my presence. Parents were also asked to complete consent forms on their child's behalf to participate in interviews and participant observation. Children were asked for their

assent to participate in interviews, and their willingness to take part was confirmed before the interview and at stages throughout the interview.

In order to support the assent process, information leaflets were developed for children. (See Appendix A). These were piloted with different children and their parents for feedback. Leaflets were designed to be age-appropriate with different leaflets for children aged 4 - 7 years, and those aged 8 - 12 years.(223) These were designed to be colourful, and used question and answer format to appeal to this age group.(216) The development of these materials raised some dilemmas: the parent group involved in reviewing the materials felt that younger children would not be interested in receiving the information and that the assent process was unnecessary in children aged 4 - 7 years as they were too young. This is not consistent with the experiences of other researchers (226): indeed, no lower limit for informed participation in social research has been established.(223) Nor is this viewpoint consistent with the premise that the ability to consent is context-specific, and related to the individual child's experience and development, rather than being purely defined by age.(223) Having considered carefully the views of the parent group and the other evidence, the decision was made to provide the information for younger children in the packs given to families, and parents were asked to share these with their child if they felt it was appropriate. Conversations with families revealed that they had found these information leaflets useful, and that they had prompted discussions with children about the research. Children were invited to sign the consent form alongside their parent if they wished.

2.5 Professionals

Professionals with experience of caring with a child with an invasive device in the community were recruited from a range of different disciplines. The recruitment of participants was informed by the experiences of children and families explored in early interviews. Inclusion and exclusion criteria were kept deliberately broad to allow the inclusion of a wide range of different professionals identified by families in the early part of the study, and are outlined in *table 2.5*.

Table 2.5 Inclusion criteria for professionals

Inclusion criteria	Exclusion criteria
<p>Aged over 18 years</p> <p>Able to give consent, and willing to participate</p> <p>Experience of caring for a child with an invasive device in the community, whether personally or at a service management level</p>	<p>Not provided written consent</p> <p>Unwilling to participate, or withdraw their consent at any point</p>

A purposive sampling frame was developed based on my review of the literature, my professional experiences, and after discussion with the parent representative. This sampling frame was modified in response to the experiences of families in phase one of this study. To avoid any risk of breaches of anonymity, formal carers were not “paired” with participating families. Rather, the families’ experiences informed the types of professionals that I then recruited. Recruitment of professionals began before completion of family interviews; however, no new groups of professionals were identified by the remaining families.

2.5.1 Recruitment

Professionals were recruited through a variety of methods. Lead clinicians were identified at each of the four NHS Trusts which had initially been used to recruit families and were invited to participate. Representatives from professional organisations identified by families (such as children’s hospices) were also invited. The lead contact was also asked to suggest an alternative contact within the organisation if they were unwilling to participate. If there was no response from the lead contact, a reminder email was sent after 2 weeks, and an alternative contact sought within the same organisation if there was no response from the original contact. If after this it was not possible to identify a lead contact, then no further contact was made with that organisation.

Study information (including a link to the study webpage) was distributed through informal contacts, professional organisations, and social media. Snowballing (inviting

suggestions from existing participants) was also used to suggest other relevant groups of professionals not already identified.(229) Potential participants could complete a postal reply slip, contact me directly by telephone or email, or complete a contact form on the study webpage. I would then ensure that the professional had seen the participant information. When a professional contacted me, we discussed the study and answered any questions that they had. It was made clear that they were under no obligation to proceed with the study. If the professional did wish to take part, a mutually convenient date and time for the interview was agreed.

I began by approaching professionals using a snowballing approach via my own working circle and from the four NHS Trusts with which I had established a working relationship during phase one of the study. Although I had a positive response, recruiting from my existing contacts meant that I had a narrow field of experiences confined to a limited geographical area. The next step was to widen the field of professionals in the study. I asked one of the consultants from my professional network to put me in touch with his colleagues. This had several advantages: first, it meant that the person I approached was likely to be the most suitable as far as an interest in research was concerned; second, it meant that the project and I were already endorsed by my professional network.

A further challenge to recruitment was that professionals were asked to participate in interviews lasting up to an hour, and that there was no financial recompense for this time. Thus, organisations either had to agree to release staff members from their duties during the working day, or individuals had to take part in their own time. Some organisations refused to distribute information about the study to their staff as they felt it was unfair to ask them to participate in their own time.

2.5.2 Data collection

Semi-structured interviews were conducted with professionals in person, or by telephone, based on issues emerging from the interviews with children and families collected in the earlier phase of the study. A topic guide was developed and was modified iteratively (see appendix B). Topics of discussion focused on: the challenges faced by formal carers during their care of the child with an invasive device; their

perception of the challenges faced by families and other formal services; and their experiences of the information needs of families in relation to infection control.

The majority of professional interviews were conducted by telephone. Consequently, I was able to interview professionals from across a wide geographical area who had different experiences. I found it harder to establish a good rapport with participants during the telephone interviews. On reviewing my interview transcripts, I found that telephone interviews adhered much more closely to the topic guide and were more structured than the interviews I carried out in person.

2.5.3 Ethical issues

All participants who were invited to take part received an information pack containing a letter of invitation to participate and a participant information leaflet. Potential participants were invited to contact me if they were interested in participating. They therefore had as much time as they wished to consider the information. I discussed the study in detail and answered any questions that they had before consent was taken. It was made clear to all participants that consent was completely voluntary and that they were free to withdraw at any time without repercussions.

Participants were asked to complete a written consent form before they took part in the study. When interviews were conducted in person, written consent was taken and confirmed at the time of the interview. When interviews were conducted by telephone, participants were asked to complete a consent form and return this by email from an identifiable email address. I went through the consent form with the participant on the telephone before the interview started, and confirmed that the participant was happy to continue.

As with the family interviews, there was a possibility that professionals could become distressed during the interview.(200) However, no interview with professionals was stopped because of distress.

2.6 Data analysis

The constant comparative method was used to analyse data from interviews with children, families, and professionals.(230-233) Themes arising from the data were organised into concepts and used to generate theories. I describe this process in more detail in section 2.6.1. It is important to acknowledge that the pre-existing concepts and knowledge of the researcher will influence the way in which the data are collected and analysed.(234) I discuss my role as a researcher and the impact this has had on this study in more detail in section 2.6.2.

2.6.1 The process of data analysis

Data analysis was an ongoing process which started with the first interview.(193) Interviews were digitally-recorded and transcribed, and additional materials produced during the interview sessions (such as drawings and worksheets) were preserved to aid interpretation. Field notes of the observed encounters were also used to enhance interpretation of the interviews. Data analysis was carried out by: identifying key concepts which emerged from the data; applying codes to each section of transcribed data; organising these codes into a structured coding tree; and using “free-writing” to develop these codes into theories.(193,230,235)

I kept a reflective diary and made notes throughout the data collection period. These notes included my thoughts about key concepts which emerged from the data. As a result, I could reflect on the interviews that I had already carried out and put new information into context.(236) Some interviews were held very close together which made it difficult to immerse myself in one case before having to move on to the other, and thus my time for reflection was limited. Beginning the process of analysis early had the advantage that I was able to explore topics that had arisen in earlier interviews. This enabled me to both explore the topic in more depth with later participants, and to check my interpretation of the topic.

Once the data collection was completed, I began by immersing myself in the data by reading transcripts in full. Coding was used as a way of structuring the data in a systematic manner (193), assisted by the use of a computer software package. A

selection of transcripts were open coded and codes were refined through drawing comparisons between individual cases.(193,198,230)

The next step was to organise the codes into a thematic structure so that I could begin to draw relationships between the different codes.(193) Rather than force the data into a pre-conceived framework, I revisited the coding structure many times to try and make sense of the complex data (193,198,230), and reflected on the themes I had identified during the data collection period. I decided to concentrate on three high-level codes initially. I then revisited the data within each high-level coding to establish sub-categories. As I worked through the data, a more detailed and complex coding structure was developed which was organised into higher themes and sub-categories.(232)

The development of the coding structure was discussed closely with my supervisors who offered different perspectives on the data which enhanced the development of the coding tree.(193,230) Sensitising concepts from the relevant literature, including theory relating to partnership between families and services, and other work helped structure the initial coding and enriched the analysis.(230,233,237) A key sensitising concept which influenced my interpretation of the data was the model of co-production, which I explore further in section 7.7. Other work on patient safety and the role of patients and families in supporting safety also informed my analysis. By using a combination of theory-driven sensitising concepts, and inductive, grounded, coding, I was able to generate codes and themes that captured key elements of my data and enabled me to address my research questions. Thus the coding framework which finally emerged from the data was shaped by theoretical constructs from the literature, reflected emergent themes from my data, and was focused on addressing the research questions which had been developed at the beginning of the study

Once the coding structure was complete, I applied the codes to the data. Computer software (NVivo 10) was used to organise the data into the high-level codes initially, and then into sub-codes.(198,200) I used my field notes to provide context and guide interpretation.(200) For interviews with children, additional materials such as drawings and worksheets also helped enhance my interpretation of the data and provided further context to the interview transcription. Drawings were not analysed in isolation as this posed challenges for interpretation and risked imposing an adult interpretation on the

data.(206,216) Rather, the additional materials helped to add context to the child's responses.

When the coding was complete, I began to explore the themes further. I found that the process of free-writing allowed me to clarify my thoughts about the relationship between themes and that I was able to interpret the coded data through the process of writing.(230) The data presented here are the result of this process of exploring relationships between different themes to generate theory emerging from the data, rather than the form in which the data were coded and organised.(235)

Each interview was analysed separately, and there was no attempt to link child and parent interviews during the analysis.(236) Data were separated out from individual interviews, organised by themes, and recontextualised across cases.(236) Rather than focusing on detailed case studies, analysis of the data aimed to identify common themes in the care of the child with an invasive device in the home.(193,236) However, the interviews carried out within a single family provided important context for the interpretation of the data collected. I revisited individual interviews and examined parent and child interviews together to maintain the context when conducting analysis across cases.(198,230)

2.6.2 The role of the researcher in interpreting the data

It is important that I acknowledge that my professional role had a significant impact on both the data collected, and the way in which I have analysed and interpreted that data.(195,200) As a paediatric registrar, I already had a measure of familiarity with factors such as the child's underlying health condition. This may have meant that families and professionals felt that they did not have to explain some terms or concepts in the same detail as they might have done to a non-professional.(195) As a result, there is the risk that we used terms but without fully exploring or sharing their meaning. In particular, reviewing the interview transcripts I noted that many of the professional interviews contain phrases which assume shared experiences between myself and the participant (participants used phrases such as "*you know what I mean*", "*well, you've seen it*", "*you know what it's like*"). I rarely challenged or probed these moments – I felt that my identity as a fellow-professional gave me an entrée into the experiences of

professionals which I would not otherwise have had and was concerned that probing deeper into these moments of shared experience would have damaged the rapport between myself and the participant.

Family interviews rarely had moments of shared experience. This was for two main reasons: first, I made it very clear to the families that I had no experience of device care in the community nor had I any experience of caring as a parent for children myself. Second, it was clear from the meeting with the parent representative that families did not feel that a healthcare professional working in an acute hospital would have any insights into the reality of their everyday lives. Thus the families were positioned as the experts in their own lives.

As I spent more time with families outside the healthcare environment, I realised how little information they shared with healthcare professionals about the challenges that they managed every day. All the families in the study knew that I was a paediatric registrar. Initially, I felt that my professional role gave me an advantage as families would be used to talking to doctors about personal matters. As I contrasted the quality of the information shared with me as a researcher to the information disclosed to me as a professional, I started to question my assumption. It is possible that families would have been more open and disclosed more to a non-professional.

Initially, I found the experiences of families were discordant with my understanding of health services and the role that families played in the provision of services. The discordance between the experiences that families shared and how I perceived my own work forced me to re-evaluate my role as a professional and influenced the interpretation of the data. As I continued to work as a paediatric registrar throughout the thesis, I was forced to confront the discrepancy between my world views: how I saw the world as a researcher, and how I experienced it as a professional. My personal reflections are to be found in section 7.10.

2.6.3 Theoretical Saturation

Before starting the study, I set a target of recruiting a certain number of participants from each group. After discussion with my supervisors and reviewing the literature (238,239), I decided that a study group of twenty families and twenty professionals

would be sufficient to explore a wide range of views and experiences, yet still be achievable within the confines of a PhD.

Theoretical saturation occurs when all categories emergent from the data are taken into consideration, allowing theory to emerge from the data.(240) Theoretical saturation occurred before the final interviews were concluded. As data analysis was carried out alongside data collection, I was able to determine that no concepts emerged from the final interviews. As such, the number of participants was sufficient to answer the questions that I had set out.(238) However, I recognise that there are limitations to the sampling framework which may have influenced the data collected. I explore these further in section 7.9.

2.7 Ethics and Research Governance

NHS research ethics committee (REC) approval was granted on the 24th October 2013. Following the difficulties in recruitment described in section 2.4.2, I applied to make a major amendment to the study protocol. The amendment expanded the inclusion criteria to include children with all invasive devices and allowed me to advertise via parent groups and social media to recruit participants. Full details of the amendment, which was granted on the 13th August 2014, are given in section 2.4.4.

There were several delays in obtaining ethical and research governance approval. Unfortunately, the final submission to the ethics committee in November 2013 coincided with the absence of a staff member at the REC and the Christmas holidays. After several attempts at contacting the REC, it transpired that the submission had not been processed when it was received, which added to the delays in gaining research ethics approval.

Similar delays occurred with obtaining Research and Development approval at the host Trust, including one month's delay when, though final approval had been granted, I was not informed. There were a number of delays confirming receipt of documents etc., and inconsistencies arose in confirming receipt of documents. Further delays arose from the time taken to clarify technical matters such as whether I needed a research passport or a letter of access for the other Trusts as a practicing clinician, and the use of University versus Trust headed paper. In one case, it took so long to go through the Research and

Development process that I had completed data collection before the approval was granted, and I was unable to recruit from that Trust.

2.8 **Summary**

In this chapter I have explored why a qualitative approach was most appropriate to examine the subject area. I have discussed the importance of seeking the views and experiences of children, families, and professionals to gain a wide view of the question at hand. The interpretation of data collected through semi-structured interviews was enhanced by observational data. Careful attention to power relationships between researcher/participant and adult/child facilitated the participation of young children, a group too often excluded from sharing their experiences. In Chapter 3, I introduce the participants in the study, before going on to explore their experiences of device care and IPC in Chapters 4 – 6.

3 Participants

I begin the presentation of my data with an introduction to the participants in this study. Twenty families (made up of parents and children) and twenty professionals took part in semi-structured interviews. I provide an introduction to the children and families who participated, including information about diagnosis, family structure, and social background. Only minimal information is provided in an attempt to avoid the identification of participants – I reflect on the limitations of this approach in section 7.9. Families' experiences of device insertion in the context of the child's medical condition are explored in section 4.1. I go on to introduce the professional participants, describing their different roles in supporting children and families. As I demonstrate in subsequent chapters, participants' experiences influenced their views on device-related infection and IPC measures. Thus this information provides important context to the data which I present in Chapters 4, 5, and 6.

3.1 Children and families

Twenty families participated in the study. A summary of the child and parent participants is presented in *Table 3.1*. This table describes the device that the child had in place at the time of the interview and any other devices that the child had had in place as this also affected their experiences and perceptions of living with an invasive device. The children in this study had a variety of different devices inserted in response to a wide range of medical needs. (These are summarised in *Table 3.1*).

Table 3.1. Child and family participants

Child	Reason for device insertion	Child participation	Age	Gender	Device	Parent(s) interviewed
C1	Cancer	Interview and observation	4	Female	Central line	Mother (M1) and father (F1)
C2	Cancer	Interview and observation	8	Male	Central line	Mother (M2)
C3	Syndrome	Observation only	4	Female	Tracheostomy; gastrostomy; bone anchored hearing aid (BAHA)	Mother (M3)
C4	Respiratory	Interview and observation	4	Male	Portacath	Father (F4)
C5	Cancer	Interview and observation	7	Female	Portacath	Mother (M5) and father (F5)
C6	Syndrome	Not present	8	Male	Tracheostomy; gastrostomy	Mother (M6)
C7	Cancer	Interview and observation	4	Female	Portacath; central line previously	Father (F7)
C8	Cancer	Refused	11	Male	Central line	Mother (M8)
C9	Syndrome	Observation only	9	Male	Gastrostomy	Mother (M9)
C10	Cardiology	Refused interview; observation only	7	Male	Gastrostomy; central line, Portacath, tracheostomy previously	Mother (M10)
C11	Syndrome	Interview and observation	9	Male	Gastrostomy; central line previously	Mother (M11)
C12	Syndrome	Interview and observation	12	Female	Gastrostomy; central line	Mother (M12)
C13	Syndrome	Observation only	8	Female	Portacath	Mother (M13)
C14	Syndrome	Interview and observation	7	Female	Gastrostomy	Mother (M14)

C15	Neurological	Not present	10	Male	Gastrostomy	Mother (M15)
C16	Neurological	Interview (assisted communication)	9	Male	Gastrostomy	Mother (M16)
C17	Syndrome	Interview and observation	7	Female	Gastrostomy	Mother (M17)
C18	Neurological	Not present	11	Female	Gastrostomy	Mother (M18)
C19	Neurological	Observation only	9	Male	Tracheostomy; Gastrostomy; central line previously	Mother (M19)
C20a	Syndrome	Interview and observation	10	Male	Gastrostomy	Mother (M20)
C20b	Syndrome	Interview and observation	6	Male	Gastrostomy	

3.1.1 Parent participants

The majority of parents that were interviewed for the study were mothers, reflecting the role they identified for themselves as primary care giver for the child. This is similar to other studies of children with chronic illness.(153) Two fathers were interviewed alone. One father (F4) described himself as sharing care for the child with the mother equally, while the other (F7) was the primary caregiver for the child. In two families (C1, C5), both parents were interviewed together. All but one family used English as their first language; and all but two families (C5, C17) came from White British backgrounds. The participants in this study are less ethnically than the general population in England and Wales where 80.5% of people describe themselves as White British.(241) Families were recruited from a wide geographical area including the East Midlands, Yorkshire, London, and Essex.

3.1.2 Children

Eleven children from ten families participated in semi-structured interviews. Another child, child 16, was beginning to use eye gaze and head movement as a means of communication: he was able to indicate a preference between two options, and to express agreement or disagreement with statements. Although he could not take part in a formal interview, this child was present during the interview with his mother and was invited to express his thoughts throughout. His contributions were not recorded as part of the field notes; however, his contributions were commented on by his mother and provoked further discussion. The participants included two brothers (child 20a and child 20b) who both had gastrostomies.

Of the remaining 10 families, the parents of seven children (C3, C6, C9, C13, C15, C18, C19) felt that their children would not be able to contribute to a conversation because of their developmental delay. Two other children refused to take part in any discussions about their device at all and were clearly distressed by talk about the device. One of these two children, child 8, was aware that I had come to talk about the device, and refused to speak to me or acknowledge my presence at all. The other, child 10, seemed quite comfortable when I was talking with his mother about his general health needs; as soon as the device (gastrostomy) was mentioned, he screamed and ran out of the room.

For both these children, parent interviews took place in a different room, out of their hearing.

3.1.3 Family structure

The majority (16/20) of the families included in this study lived in two parent households. Although both parents undertook aspects of device care, the mother usually acted as primary caregiver for the child. Four families were single-parent households (C7, C10, C13, C19). In three of these families, the mother was the sole care-giver and was responsible for all device care not provided by professionals. There was little contact or support from other family members. In the remaining family, the mother and father lived in separate households but shared the care of the child between them. All but two of the children (C7, C19) had siblings who lived in the family home.

3.2 Professional participants

Interviews were conducted with twenty professionals were recruited from across a range of clinical and non-clinical roles (*Table 3.2*). All roles had been highlighted by families as important in the management of device care. Nine participants (professionals 1, 2, 6, 9, 10, 15, 16, 17, 20) were recruited through NHS Trusts which were also involved in recruiting families, and a further eight participants (professionals 3, 7, 8, 12, 13, 14, 18, and 19) were recruited through professional contacts and snowballing. Two participants (professionals 4 and 5) had been shown the social media post by a parent, and one participant (professional 11) came across the study on social media. One professional (P8, a founder of a support group for parents of children with cancer), was able to reflect on her own past experience as a parent of a child living with an invasive device, as well as discussing her role in supporting other parents.

Different professionals had varying experiences of device care, and of working with families to support the care of the child with an invasive device. Some professionals looked after children exclusively in a community setting while others were based in hospitals. I open this section with a description of the professionals who participated in this study, including their working history, which gives some context to their contributions to this study.

Table 3.2. Professional participants

Professional	Role
P1	Oncology day care nurse
P2	Oncology day care nurse
P3	Oncology Consultant
P4	General Practitioner
P5	Community Nurse
P6	Play specialist based on oncology ward
P7	Teacher (school for children with additional needs)
P8	Founder of support group for parents of children with cancer
P9	Play specialist based in the community
P10	Healthcare Assistant based on oncology ward
P11	Community Nurse
P12	Ward nurse
P13	Junior doctor with interest in oncology
P14	Junior doctor with interest in oncology
P15	Oncology Consultant
P16	Oncology Consultant
P17	Community oncology nurse
P18	Community nurse
P19	Community nurse
P20	Oncology nurse with experience of community and hospital care

3.2.1 Community nurses

Community nurses provided technical device care for children in the community on a planned basis. Children were visited at home at regular intervals so that bloods could be taken from central lines or Portacaths; these devices were also flushed regularly by community nurses and inspected to make sure that they were in good condition. Some nurses helped families to carry out device care that required additional pairs of hands or expertise, such as changing gastrostomy buttons or tracheostomy tubes.(P11, P17, P18, P19) Support was provided outside of the family home: community nurses worked closely with schools to ensure that children could receive safe care when they were at school and away from their families. One nurse spent half his working week providing education and support in schools so that teaching assistants and carers could carry out device care.(P11) If school staff did not feel that they were able to care for the child, then nurses had to provide additional support. Such support posed a significant time burden on community nurses, but was essential for the child to be able to attend school.

“I have signed them [teaching assistants] off as being competent, but they are still not confident enough to be left on their own with her, and they still need a registered nurse at the moment.”(P11)

In addition to providing technical care for the device, these nurses felt that the regular contact with the family provided additional reassurance for the family. One community nurse explained that she visited families every week to provide central line care. The visits gave families an opportunity to raise concerns that were not directly related to medical care, such as problems with school.(P17)

“That line flush every week for some of them, is their contact with medical staff.” (P17)

The regular contact meant that community nurses could build close relationships with their patients, learning vital information about their needs.(P17, P18) Nurses could liaise with other professionals to share family concerns, and access other support if needed.(P18)

“We tend to be sort of the key worker for the families, and we tend to kind of direct and get people involved and continue liaising with them throughout really as well as supporting the family.” (P18)

One nurse explained that he saw families as retaining overall control over their child and the care that they received, and his role was to support them in caring for the child.(P11)

“When you’re in their home they’re kind of in charge. So they’re in charge, you’re a resource, and you can possibly lead them in a particular direction... but primarily when you’re a community children’s nurse, they are actually in charge” (P11)

The community nurses in this study felt that their role was to ensure the wellbeing of the child by supporting the family, rather than by insisting on adherence to particular aspects of device care. Only in very exceptional circumstances, for example if there was a clear and immediate risk to the child, would the nurses impose their views.

3.2.2 Day care nurses

Two nurses (professionals 1 and 2) worked in a specialist day-care unit for children with cancer. The children they cared for attended the day-care unit on a regular basis to receive chemotherapy or blood transfusions. Although the interaction between the families and nurses took place in the hospital, the children were not admitted as in-patients and the care of the device was primarily undertaken by their families (as outlined in chapter 4). Despite being based in the hospital, these nurses felt that their role was primarily to support families to care for their child at home.(P2)

“My role is to ensure that day care is as smooth and straightforward as possible allowing patients more time at home.” (P2)

The nurses provided specialist telephone advice for families while they were at home, and provided a link between the families and other professionals such as community nurses, specialist doctors, and general practitioners. As a result, the day care nurses were able to provide additional support for families if other professionals had concerns.

One example of this was if community nurses felt that families were struggling to cope with the pressures of the child's illness and maintain the level of hygiene necessary to keep them safe.(P2)

"It could just be their lifestyle, the way they live. That is why when the community nurses go in sometimes they report back that they have been to a particular house and it looks like they might need some support from social care, then we will put that into place to be able to go out and help them." (P2)

Thus the responsibility of the day-care nurses was not confined to the care provided in their workplace, but also extended to the child's home.

3.2.3 General practitioners

Only one general practitioner (professional 4) took part in the interviews, reflecting the recruitment approach which did not approach general practices directly. This also reflects the experiences of families who reported little contact with their general practitioner, and is consistent with the findings of other researchers.(41) This particular general practitioner was based in a geographically isolated location. Children in their area with invasive devices faced long and arduous journeys to reach the specialist hospital which oversaw their care, and specialist nurses from the hospital were not able to travel to provide device care in the child's home. Therefore families contacted this particular general practitioner or a community nurse in the first instance if there were any concerns about the device, and additional support was provided by video-link to the specialist hospital. Within a small community, the involvement of the general practitioner provided continuity to families who had seen the same healthcare professionals throughout their child's life.(P4)

"So we've been involved as GPs and community hospital doctors, we've been involved with her since she was born." (P4)

The involvement of the general practitioner in this setting meant that children could be cared for at home, without frequent trips to the hospital.(P4)

“But the most important thing that keeps this child living at home with her parents without risk of serious deterioration is the Portacath and looking after that is the most important thing.” (P4)

The general practitioner’s role was to maintain the child’s home life by supporting the family with device care.

3.2.4 Physicians

Five doctors took part in the interviews: three consultants (P3, P15, P16), and two junior doctors (P13, P14). All worked exclusively or primarily with children with cancer. The vast majority of the contact between doctors and families took place in the hospital during admissions when children were unwell or for a planned course of treatment. Children and families also interacted with doctors during planned clinic visits or in the day-care unit. Doctors had little contact with children outside of the hospital environment, apart from one consultant who provided medical cover for a children’s hospice in his local area.(P3) As a result, their role was largely confined to supporting families around the time of device insertion and managing any complications that arose, such as infection.(P3, P15)

“My involvement with the implanted devices is talking about them in the first place... then it is sort of things like remembering to ask how they are getting on with it really rather than providing particularly specific advice or engaging in their management at a preventative level.”(P3)

Some doctors felt that device insertion was a routine part of care for serious diseases, such as cancer.(P3, P16)

“I think we do assume that everyone is going to have a line.” (P3)

The assumption that children with cancer would have a central line inserted may have been influenced by the benefits of line insertion that professionals witnessed in their daily work. Using a central line could minimise the distress for the child, but it was also technically easier to access compared with inserting a cannula.(P13)

“We just pop them in because it’s easier.” (P13)

Doctors saw invasive devices as a better option for the child, and a normal part of the care that they provided.

“Pretty much all of my patients who are on treatment have a central line of some description.” (P15)

Doctors saw children if there were concerns about the device when they attended the day care unit, and when children were admitted for the treatment of device-related infection. Thus for doctors, both device insertion and device-related infection were familiar occurrences.

3.2.5 Ward nurses and healthcare assistants

Two of the nurses who took part in the study were based in hospital and cared for children if they were admitted as in-patients.(P12, P20) One nurse had worked on a high-dependency unit of the local hospital for many years.(P12) Children in the area usually had a device inserted at another hospital before returning to the local hospital before discharge home. Part of her role was to train families in the care of the device before discharge home, thus she was aware of the restrictions that a device could place on family life. Despite her involvement in supporting families around the time of device insertion, she had little contact with them outside the hospital; her experiences were mainly of caring for children with invasive devices who were admitted when they became unwell.

The second nurse had extensive experience as a community nurse and had only recently started working on a hospital ward.(P20) She explained that there were differences between working in the community compared to working on a hospital ward. In the hospital setting, there was more nursing control over how device care was carried out and there was additional professional support when it was needed. Notwithstanding the setting, she felt her role was to support the child to live as normal a life as possible. (P20)

“Getting them back to their normal life as much as possible after their diagnosis.” (P20)

Both nurses cared for children who were admitted to hospital as a consequence of device-related infection.

3.2.6 Non-clinical professionals

In addition to the clinical professionals outlined above, families were supported by non-clinical staff in the hospital, at home, and in the wider community. Non-clinical staff in this study included a healthcare assistant, school staff and play specialists.

Hospital staff worked alongside healthcare assistants. One healthcare assistant had worked on a children’s cancer unit for many years. Her role complemented that of the doctors and nurses as she provided information about the device before insertion, and helped families with daily care such as bathing after the device was inserted. By giving this support, she was able to suggest practical ways that families could adjust to caring for the child with the device in place.(P10)

Play specialists were based both in hospital (P6) and in the community (P9) – they supported children through painful procedures through play techniques which distracted the child from the procedure. They also provided emotional support for the child and the family. Although they did not have a clinical role, they contributed to clinical discussions about device insertion and provided insight into how the family would adjust to the device. Sometimes, the play specialist provided information that influenced whether a child had a central line or a Portacath inserted. The play specialist had sometimes supported the child through other invasive procedures, such as cannulation, and used the child’s response to the procedure to feedback to the clinical team.(P6)

“We’ve usually found out how the child reacts to invasive procedures... So with that in mind we try to make a decision that the port would be better or the line would be better.”(P6)

Before device insertion, play specialists used role play to explain to children and families what the device was and why it was being inserted. Dolls and teddy bears had

devices inserted and children were encouraged to care for the device in the toy. The play specialists felt that explaining the device to the child before it was inserted helped the child adjust to the change in their body.

“If they’re prepared properly we find that children cope with it really well.” (P9)

Not all children adjusted to having a device inserted – play specialists in the community worked with children in the home or at school to encourage children to comply with device care. By working with children and families, play specialists were able to broker agreements about how device care could be carried out.(P9)

“They know they have to have it done but they can choose whether to lie down or sit up...” (P9)

Play specialists were thus in a position of supporting cooperation with device care while giving the child a feeling of control over what was happening to their body.

A teacher in a school for children with special needs explained that invasive devices were common in her school.(P7) Teaching assistants carried out device care in school, such as giving gastrostomy feeds or changing dressings. Although the teacher did not carry out technical care herself, she ensured that device care was integrated into the class routine. The class timetable was organised so that children’s feeds were given at the appropriate time, and equipment was transported whenever the class went on a trip.

“It is just part of your daily routine... you sort of get used to thinking about it.” (P7)

This perception of the device as a routine part of school-life was influenced by the teacher’s work in a school for children with special needs. All the children in her school had additional health needs of some form and the teacher saw an invasive device as part of the child’s needs. Supplies of equipment to carry out device care were readily available at the school. All the teaching assistants received training in device care from community nurses, and additional support was available from nurse assistant who was based at the school. The care of the device was part of the system of care established in the school which was supported by equipment and human resources.

Parents and families could obtain support via parent groups and patient charities. The founder of one parent support group had herself been the parent of a child with cancer, and now supported other parents by providing information on treatment pathways and device care.(P8) She had personal experience of trauma of device insertion at a time when her daughter had been very unwell, and had vivid memories of that time. As well as drawing on her own experiences she was in contact with a number of families whose children had cancer, and she was aware of the challenges they faced in everyday life. At the same time, she worked closely with clinicians and recognised the difficulty of entering into the families' worlds too closely.(P8)

“It is really important that the clinicians understand the quality of life implications for every decision they make. However in order to be able to make these decision and do this work and torture these children with poison and medication and maim them with lines and ports, you have to have that professional detachment.” (P8)

3.3 Summary

In this chapter, I have provided a brief overview of the child and family participants in this study, commenting in particular on family structure and support networks. I have provided only limited information about diagnosis as some children with rare and complex medical needs may be identifiable. I have provided more detailed information about the roles of different professionals involved in the care of the child as this provides important context to their experiences of invasive devices and IPC in the home. I go on to explore the experiences of children and families during device insertion in Chapter 4.

4 Children with invasive devices

This chapter describes how device care is carried out in the context of everyday life. I begin by exploring the reasons for device insertion and the resulting impact on family life as children and their families adjust to life with an invasive device (section 4.1). In section 4.2 I go on to describe how the care of the device is organised, and outline how the technical care of the device is carried out while families strive to maintain a normal family life. The emotional impact of managing device care is outlined in section 4.3. The chapter concludes by examining the challenges of maintaining the device when the child is away from the family circle, using attendance at school as an example in section 4.4.

4.1 Reasons for device insertion and adjusting to life with an invasive device

Families faced different challenges which they responded to using a variety of strategies. Working with professionals in a form of co-production allowed families to meet these challenges with strategies which appropriate for their individual circumstances. In this section, I describe the patient journey that led to device insertion and how children and families adjusted to life with a device. Device insertion was a gradual process for some families, or occurred as an emergency situation in other cases. Some families had experience of both emergency and planned device insertion throughout the child's illness.

4.1.1 Device insertion as a gradual progression in the disease

For some children, the decision to insert an invasive device was a gradual process, taken over a period of months or even years. These families had time to think and prepare for the device insertion.(F4, M9, M10, M11, M12, M13, M14, M15, M16, M17, M18) The need for a device was not an emergency but became increasingly urgent over time as families (and medical staff) usually felt that alternatives were no longer viable. This occurred, for example, in relation to gastrostomies, which were used to support children with difficulties in swallowing or absorbing food. Some children were receiving special milk feeds through a nasogastric tube which provided them with adequate nutrition. (M9, M14, M15, M17) However, there were difficulties with using the nasogastric tube for a prolonged period of time. The tube could be pulled out or came out easily when

the child vomited. Nasogastric tubes were also used to give medications, yet some commonly used medicines could also block the tube. As a result of these complications the nasogastric tube frequently needed replacing, often requiring a trip to hospital. Thus the gastrostomy came to be seen by families as an acceptable alternative to the nasogastric tube.

“By the time you get to gastrostomy level, you’ve had to go through quite a bit already, you know, you don’t suddenly wake up one morning and then say oh, my child needs a gastrostomy, so your journey’s probably been quite bumpy to that point.” (M14)

Central lines and Portacaths were inserted when children needed regular blood sampling or required intravenous medications such as antibiotics. It could be technically difficult for doctors to insert peripheral cannulae in these children, and there would often be multiple attempts resulting in pain and distress for the child.(M8, M11) One boy required frequent courses of intravenous antibiotics as part of his treatment. Although the medication had initially been given through a peripheral cannula, as time went on, the procedure became increasingly difficult. As a result, the boy suffered considerable distress and his treatment was delayed. The boy had a Portacath inserted which meant that he could receive treatment without further cannulation.(F4) Another girl had a Portacath inserted so that blood samples could be taken. As part of her medical treatment, she required weekly blood samples to be taken to monitor levels of medication and tailor the dose of her medication. Peripheral blood sampling was technically difficult and resulted in significant distress to the child. The Portacath was a more reliable method of ensuring vascular access: it was often quicker to use than peripheral sampling and therefore less upsetting for the child. It had the added advantage that community nurses could use the device, and thus avoided trips to hospital.(M13)

“I think for me the port has improved our quality of life so much, because we’re not going to the hospital all the time.” (M13)

These examples demonstrate how families supported device insertion as a way of reducing the impact that the child's illness had on everyday activities, allowing them to live a more normal life.(242,243)

Even where there were clear indications for device insertion, and parents agreed that it was necessary, the decision to proceed was nonetheless often a difficult one. The insertion of the device resulted in a permanent and physical change to the child which parents found very difficult to accept.(F4)

"It felt quite a symbolic step to have this permanent thing."(F4)

The surgical procedure to insert the device could be time-consuming and disruptive. Delays in carrying out the procedure gave some parents time to reflect on their decision, and to wonder if they were doing the right thing. One mother explained that the insertion of her son's gastrostomy had taken place at a specialist hospital at some distance from the family home. There was no scheduled date for the procedure, and instead the child was placed on an "emergency theatre list" which placed children in order of priority. As her son's operation was not an emergency or urgent procedure, the operation was delayed for several days. During this time, the mother had to manage the uncertainty of waiting for an operation, away from her home and family network, leading her to question her decision.(M9)

*"Having to go to [Location 2] and then he was put on the emergency list. I understand that emergencies came in, but there were days of ... but there were days when I thought really, shall we just go back to an NG [nasogastric tube]?"
(M9)*

Inserting a central line was an attempt to mitigate the pain and distress of repeated cannulation, as the device could then be used to take blood or to give medications. However, inserting the device would then place the child at risk of infection.(M6, M8, M11) The additional risks associated with a central line sometimes resulted in families being reluctant to have one inserted. A family whose son had had both a tunnelled central line and a Portacath in the past were keen to avoid having another central line inserted in the future. The child wanted to have a central line inserted because he was

concerned that without the line, he would have to endure repeated attempts at blood sampling and cannulation. His mother was keen to avoid a central line because of the associated risk of infection. Instead, they had compromised by having a peripherally inserted central catheter (PICC) placed during a hospital admission. Families had to balance the benefits that the device would bring against the additional responsibilities that they would have to take on to maintain it.(M11)

“[child], last time he was in, wanted a Hickman [central] line, didn’t you, you were very very cross with me when you came out with a PICC line. We had quite a big fight about it, it was the first time we’d had a proper disagreement about what he should have. That he was desperate for the Hickman line, because he hates having blood taken, and I was desperate for him not to have a Hickman line, because of the responsibility that goes with it” (M11)

If a child already had a device in place, the decision to insert a second device was influenced by the additional risk of device-related infection. The mother of a child with a gastrostomy explained that it had been suggested that her child have a Portacath inserted because he required frequent courses of antibiotics and cannulation was becoming more difficult. Although she recognised the advantages of the Portacath, she was concerned about the risk of infection, and the Portacath was not inserted.(M6)

“I’m glad they didn’t in the end. At the time it seemed a good idea, but glad they didn’t” (M6)

Parents were also concerned about the risks of device-related infection were further increased if the child had a suppressed immune system. One boy had already had a gastrostomy inserted. He had frequent chest infections which required intravenous antibiotics, and the medical team suggested that a Portacath would help administer these. His mother was concerned because her son already had problems with gastrostomy site infections, and was under investigation for immune deficiency. After discussions with all the doctors involved in the child’s care, a decision was made not to insert the Portacath because the boy would be at increased risk of infection from the device.(M9)

“So we’ve decided until we know exactly what we’re doing, no port... just I’m terribly worried about the, he gets so many infections anyway that it’s just another place for there to be infections really” (M9)

Families recognised that device insertion presented significant advantages for both child and family. Notwithstanding these advantages, the decision to proceed with device insertion signified a traumatic point in the child’s illness, and families found the decision to insert a device a difficult one. Despite agreeing to proceed with device insertion, families still had concerns about the changes in their child’s body, the additional burden on the family, and the risks associated with the device. These concerns became more apparent as device care became part of the child’s everyday life.

4.1.2 Device insertion as a sudden and unexpected event

Not all families had time to accustom themselves to the idea of an invasive device. Some children had devices inserted as emergency or urgent procedures, leaving families little time to come to terms with the idea. In some cases, healthcare professionals and families would have preferred not to proceed with device insertion, but felt that there was no alternative.(M6, M10)

One boy required numerous medical procedures and operations. He had already had a gastrostomy and a tracheostomy inserted, and his mother and the medical team overseeing his care were keen to avoid further device insertion. However, it was becoming increasingly difficult to insert the peripheral cannula which were needed to carry out further operations safely. During one operation, the surgical and anaesthetic teams were unable to place a cannula, and a Portacath was inserted as an emergency procedure.(M10)

“They came back from theatre with an emergency consent form from the anaesthetist saying we need to put a Portacath in” (M10)

Another boy was born with a syndrome which meant that his nostrils were completely blocked and he was unable to breathe through his nose. He had recurrent breathing problems as a baby, but his parents and medical team hoped that these would improve

as he grew older. Unfortunately, he stopped breathing completely and had to be resuscitated by his parents before being rushed to hospital. A tracheostomy was inserted as a life-saving procedure.(M6)

“He stopped breathing twice, his heart stopped the second time. So by then it was like yeah, OK, if you want to put one [tracheostomy] in that’s fine, off you go.” (M6)

Some of the children in this study were receiving treatment for cancer. The child could become unwell, receive a life-threatening diagnosis, and have a device inserted within a matter of days or weeks.(M1, F1, M2, F5, F7, M8) By this point, children had undergone numerous procedures during a time of great turmoil for them and their families. Children were already scared of procedures, and were apprehensive of further intervention. Responding to the child’s fears added to the emotional strain on families.(M2)

“He did say to us that there was only twice in the whole of this process that he has been really scared and one was the chest drain and two was when he was going down to have his line in. He said he was really scared.” (M2)

Thus the period leading up to device insertion was a traumatic time for both children and families. The emotional trauma around the time of device insertion influenced both the decision-making process (M10) and how the device came to be viewed later.(M8, M9) One mother explained that she did not feel that she was able to fully consider the implications of device insertion at the time.(M10)

“You’re so full of turmoil, you know, emotional disruption from the situation, there’s no way you could be counselled into making a sensible decision at that point. So it’s like asking somebody, you know, I don’t know, it’s a massive gamble with someone who’s not mentally coherent at all.” (M10)

Device insertion for these families took place at a time of great stress. The necessity for the device resulted from the child’s illness; thus, its insertion was linked in the parents’ minds with the severity of their child’s condition. Parents felt that they had little choice

but to proceed with device insertion, even though they were unable to fully grasp the implications of their decision.

4.1.3 Preparing families for life at home

Family members required training in device care in order to ensure that the child was safe at home. The child could not be discharged until the family were assessed by healthcare professionals, and deemed to be safe and competent in providing device care. As a result, families were under pressure to learn what they needed in a short time frame.(M6)

“They said that we then couldn’t go home until we’d learnt how to do it [tracheostomy care]. So we learnt as fast as we possibly could.” (M6)

Although parents were expected to complete a package of training in device care, some parents did not feel that they had received adequate training in the care of the device at home before they were discharged.(M1, M11, M17)

“But I wouldn’t say we had much training. They just said don’t let it get wet in the bath and left us to it to be honest I would say.” (M1)

In some cases, parents had to track down professionals in order to learn how to care for the device. One mother explained that her daughter had been admitted to hospital, and in the course of her admission, a gastrostomy had been inserted. Training was given on administering feeds, but not on the care of the gastrostomy. On the day of discharge, the mother sought out the specialist nurses on another ward, and received basic instructions on how to change the gastrostomy button. She received no advice about infection control, or how to identify possible infection.(M17)

“They were going to discharge her around four o’clock, and still no one had shown me how to do it. So I went over to the stoma nurses on the surgical ward and I asked them to show me...no one told us what to look out for, what looks like infection, granuloma”(M17)

Where families had received training, it did not always reflect the realities of their life at home. Families took the training that they received from professionals in hospital and adapted it to fit with their lifestyles.(M19)

“I was trained by the staff in hospital... you learn your own way of doing things... what works for you and in your home, your family” (M19)

Parents actively sought out training on device care, and developed expertise in caring for the device at home beyond the training that they received in order to provide the best care for their child. By gaining this knowledge and expertise, parents were able to care for the child while maintaining as much normality as possible.(162,244,245)

4.1.4 Fear and apprehension

Parents often reported that they were fearful of the device and the risks it posed for their child. They were worried that any injury to the device (e.g. if it was pulled or hit) would also injure their child and cause them pain. This fear pervaded every aspect of life, such as bathing or going to school, offering no respite. The alien appearance of the device reinforced the idea that the child could not be treated in the same way as they had been before the device was inserted.(F4) The device changed the child’s body and made it appear more vulnerable.(246,247)

“It just kind of looked like the kind of thing you wouldn’t get water on, it’s a very medically looking thing” (F4)

Families recognised that the device was a significant medical intervention with potentially life-threatening complications. If the device was pulled or damaged, there could be immediate and serious consequences. In some cases, parents worried that the device could result in death, especially if a central line was pulled out and significant bleeding occurred.(M2) Other children were so dependent on their device that if it stopped functioning properly, it posed a threat to their life.(M10)

“Everybody was bending over backwards to make sure that we didn’t kill him!... they’d never had a child who’s heart was so precarious, with the ventilator at home” (M10)

Even where there was no immediate threat to the child's safety, parents were still fearful of the consequences of the device failing. The device was inserted for medical reasons, and thus would usually need to be replaced if damaged. Parents were worried about the physical and psychological impact on their child of further surgery, and were keen to avoid this if possible.(M2)

"The last thing I want is for it to come out or to bleed or to have to come out and be replaced" (M2)

In some cases, using the device increased the risk of such an injury. One example was that of children who used a central line for PN. The catheters of the central line were connected to medications or feeds via fine tubing. Children who required PN could be connected to a bag of feed for up to twenty hours a day. The feed could weigh several kilograms and was suspended from a heavy and cumbersome stand. If the stand fell this would pull the line and causing pain to the child and damaging the central line.(M12) Parents were concerned in the hospital setting, where electronic pumps attached to a metal stand were used to deliver medications.(M1)

"When you are on the machines you are scared in case you pull them like when you are moving the machines around" (M1)

Social interactions were also affected as parents became fearful of physical contact and the impact that this could have on the device. Parents were concerned that picking their child up could put pressure on a Portacath, or that carrying a child out of the car would damage their central line.(M2, F4) Some families accepted the restrictions on their everyday lives, limiting their child's activities as a way of averting fear.(245,248) For example, siblings who were used to sharing a bath were no longer able to do so because of the fear that the central line could be pulled or damaged.(F1)

"We wouldn't put [brother] in with her because he might wonder what they are [central line] and pull them" (F1)

When a child had a device, everyday routines became filled with fear. The presence of the invasive device affected every aspect of the child's life – an example of biographical disruption where existing understanding of the child and how they interact with the

world around them is altered by the presence of the device.(245) Activities which had previously been seen as a normal part of childhood, such as playing with peers and siblings, now posed a risk to the device and the child.(M2, C2, M6, F7) Parents tried to support their children to continue their normal activities, even though there were concerns that the device could be damaged or the child injured.(F1, M9) Parents improvised protective measures to protect the device and exercised additional vigilance to make sure that the child was not hurt.

“So like the soft play centres, we put a bandage around her so it is nice and tight and held in and we have had no problems. You wouldn’t know. She jumps around. She will slide on her front. We have had a couple of times when they have pulled and bled.” (F1)

Activities such as going on holiday became overwhelmingly complex for families. Families had to have ready access to medical facilities in case the child became unwell.(M10) Prepared feeds and medications needed to be kept cool, therefore access to a fridge was essential.(M3) Children with tracheostomies needed access to oxygen which was ordered in advance and delivered to their destination.(M6) It was not easy to replace feeds or equipment if these were not taken with the child.(M6, M9) Some families carried two suction machines with them, in case the first one failed.(M6) Families made contact with local hospitals before their arrival, alerting them to their child’s needs in case of emergency.(M6) Children with devices also faced difficulties at security checkpoints in airports. Families struggled to explain to airport staff that their child could not pass through a metal detector; feeds and medications were scrutinised.(M8) The additional labour that resulted spoilt the pleasure of going on holiday.

“That takes the sheen off the nice trips... the logistics of it are fairly horrendous.”(M8)

Parents decided that the benefits to the child of continuing these activities outweighed the risks of damage to the device. This was not to say that they minimised the risks; rather, they chose to take these worries on their own shoulders.(F1, M2, M18, F7)

*“Has the button stopped her? No. It’s made me extra cautious and extra wary”
(M18)*

*“As much as you want to try and protect him you also have to let him have that
little bit of freedom but I am constantly on edge” (M2)*

Families had to adjust to a new reality where everyday activities were now filled with fear – further reinforcing the change that the device had made to their lives.(243,245,249) As families adjusted to this new reality, they became used to living with these fears.(250) Parents’ concerns re-surfaced when families engaged with outside agencies, such as schools and community nursing teams. In order for organisations to create action plans, families were asked to write lists of everything that could go wrong with the device. Detailing the risks inherent in their everyday lives reinforced the fear in their own mind, further illustrating how families undertake significant emotional labour to cope with the everyday reality of living with a child with an invasive device.

*“You have to overthink things and over-explain things, and everything sounds so
much worse on paper” (M11)*

Fear of the device influenced the decisions that parents and children made in their everyday lives, and contributed to the emotional load that families carried as a result.

4.2 How device care is organised between families and professionals

Families and professionals shared the responsibility for maintaining the device itself. In this section, I describe how children, families, and professionals shared responsibility for device care when the child was in the family circle.

Children with invasive devices interacted with a wide range of different healthcare professionals who had varying input into device care. These professionals were spread across community teams, local hospitals, and specialist hospitals. In addition to the professionals who were employed by health or education authorities, some families had experience of direct payments which allowed them to pay for carers to help with ongoing device care.(M3) These carers were not usually registered nurses, but were trained and aware of the importance of device care. Carers accompanied the child to

school if they needed additional support, or could provide assistance and respite for families.(M3, M15, M19)

“We’ve got a community paediatrician, speech and language, dietitian, optometry, ophthalmology, orthotics, physio, occupational therapy, disabled social working children’s team. I think locally that’s it, but then...broader a field we’ve got gastroenterology, neuro, specialist SALT (Speech and language therapy) dietitian down there as well. We’ve got occupational therapy and physiotherapy down in [Organisation 1] as well.” (M14)

The different professionals involved in the child’s care often worked in different locations and for different organisations. As a result, some families felt that there was little clarity about responsibilities between the teams. One mother felt that this confusion had contributed to the lack of support they had experienced when her daughter was first discharged with a gastrostomy. It was unclear which of their three hospitals took responsibility for the gastrostomy care, and for ensuring that the family were trained and supported at home.(M17)

“Between the three [hospitals], no one knows anything” (M17)

The care of the child with an invasive device was carried out by a complex network of family members and professionals whose roles were not clearly defined.

4.2.1 Technical tasks undertaken to use the device

The extent to which families and professionals shared device care varied greatly depending on the device and the families involved. Some devices required ongoing attention to be maintained safely – this care was undertaken by families.

Tracheostomies could easily become blocked with secretions at any time of day or night. If the tube became blocked, then the child would be unable to breathe. In order to prevent this happening, parents had to use a small flexible catheter attached to a suction machine to remove the secretions.(M3) Children could not be left unattended at any time in case the tube blocked and they stopped breathing. Parents had little opportunity for sleep as they had to be vigilant in case the tracheostomy blocked during the night.

“I would sit up, you know, I’d be awake all one day, and then sit up overnight, and then have the next day as well.”(M10)

Children who were gastrostomy-fed could require multiple feeds during the day, in addition to medications.(M6, M9, M14) Night-time feeds were often interrupted by problems with the electronic pumps used to deliver the feed, which beeped repeatedly throughout the night, interrupting parents’ sleep.(M14, M18) Although usually insignificant, parents had to be vigilant as these alarms could indicate a serious problem with the feed. Some children were dependent on the feeds and could become very unwell if the feed was interrupted or delayed.(M11) Parents had to make sure that they had all the feeds prepared and with them at all times, and exercised constant vigilance to ensure that the feed was being delivered correctly.

“He drops his blood sugar if he’s off the feed too long,” (M11)

Families spent a lot of time managing the effects of the invasive device. Feeds could leak from the gastrostomy site, or from the bag of feed, covering the child in milk.(M9) Feeds were poorly digested because of the child’s condition and children sometimes soiled themselves.(M6) Tracheostomy secretions could be swallowed by the child if they were not suctioned regularly. As a result of swallowing these secretions, the child would be sick, further adding to the families’ workload.(M3, M10, M15)

“You know, if she’s only going to sick it up anyway, then it’s like a bed to change at 3 in the morning, which – to me, that’s the worst thing. You know, when you’re tired and it’s just one more thing that you don’t want to do” (M3)

In general, central lines and Portacaths were used less frequently. Children with Portacaths experienced little change to their daily lives when the device was not being used. The device had to be accessed with a needle, and flushed with sterile saline on a monthly basis. Applying anaesthetic cream or spray before the needle was inserted decreased the pain associated with accessing the device.(C4) Community nurses visited the child at home in order to do this to minimise the disruption to family life. Nonetheless, families were restricted by these visits, and had to plan their precious leisure time around them.(F4, M10)

“We don’t usually make big plans, maybe to see other family but nothing that’s going to need a schedule” (F4)

The technical care of Portacaths and central-lines was usually undertaken by community nurses or when the child visited hospital. Some children had blood samples taken from a central line or Portacath once a week – the community nurse would visit the child at home or at school to use the device and take the blood samples. Visiting the school to take bloods from a central line minimised the disruption the child’s normal life. (C1, C2, C7, M13)

“So when she was having it accessed in school, the community nurses go in, take an hour out of her day, she doesn’t have to leave school, she doesn’t have to go anywhere, so that’s really good.(M13)

The parents of children with central lines and Portacaths were not usually trained to use the device, yet they remained responsible for its maintenance and care during everyday life as I explain in section 5.3.

4.2.2 Families undertake additional technical tasks to care for their child

Some children used their central line daily to receive medications or intravenous nutrition. The frequent use of the device meant that the care had to be provided by a family member. The parents of these children were trained to use a central line to take bloods, and give medications, thus they received comparatively little input from community nursing teams.(M10, M12) Other families were motivated to take on more device care in a bid to regain control over their own lives.(M10, M18) Regaining independence in this way empowered parents at a time when things seemed beyond their control (162), and when professionals were in charge of managing their child’s care.

“I’m not going to be reliant on a nurse” (M18)

“I learned how to access that so I could do routine flushing and things to stop, just to prevent us as a family being trapped in by appointments and waiting in half a day for community teams” (M10)

Some families felt that by undertaking device care themselves, they could ensure the care was delivered in a way that felt “normal” to them, and which fitted with their family life.(M10, M15)

“It’s important to me that in this house and within our family, [child] is normal, and normality comes out of being able to treat the stuff the comes along with his life as routine as possible”(M15)

For some parents, carrying out device care resulted in a better family life for their other children as they were able to spend more time at home.(M9, M10, M11, M15)

“The other two [siblings] hate it when I’m in hospital, so I tend to try and do as much as I can from home” (M9)

This is one example of how families take on an additional workload in order to minimise the disruption to the normal life of child and the wider family.(243,251,252)

4.2.3 Families use their technical expertise to support professionals caring for their child

Carrying out device care was experienced as empowering for some parents, as they could demonstrate their skill and expertise to healthcare professionals, gaining respect from the clinical team as result. One mother felt that it was a sign of respect from nursing staff that she was trusted to access her son’s Portacath on the ward.(M10)

“There’s a real partnership feeling there, that is empowering” (M10)

However, families also described instances where their technical expertise was used to support professionals to deliver device care outside of the home. Rather than empowering families to carry out device care, some families felt that their expertise was used to replace the care they expected professionals to provide. One child was offered time at a local hospice so that her family could have some respite from providing her care. However, her mother explained that the staff at the hospice were not trained to use a central line. The child was dependent on PN (parenteral nutrition) delivered through the central line. Thus the only way in which the child could use the services at the hospice was if her mother accompanied her at all times.(M12)

“She goes to the children’s hospice, but I still have to stay with her, they won’t have her on her PN without me there” (M12)

Parents also supported medically trained professionals in a healthcare environment. One mother described how each time her son was admitted to her local hospital, she had to talk the staff through the care that he required to ensure that he was safe. Each time her son was admitted to that ward, she had to check with the staff that they had the appropriate equipment to care for the device and that her child was nursed near the nurses station in case the tube blocked.(M6) On one occasion, this mother had to rush to hospital to perform an emergency tracheostomy tube change on her son who was struggling to breathe, as none of the medical or nursing staff were trained to carry this out.(M6)

“They rang me up and said that they thought he was struggling to breathe, and I said so, have you done a tube change? Well nobody’s trained so I said alright, would you like me to come up and do one then? Yes, she said well not even the on-call doctor can do it. So, two in the morning I had to go up and do a tube change, at the hospital.” (M6)

Another mother was advised by the specialist hospital that she should learn to access her son’s Portacath because *“there isn’t always staff on a hospital ward who can access [the central line]”*.(M10) Even in hospital, parents were sometimes viewed as trained carers who could provide support to other members of staff.

Families were concerned that if they did not provide this support for professionals, their child would suffer as a result. Providing this support required knowledge of the health and social care services, skills to navigate through the services, and experience of working with different services. In this way families acted as managers of their child’s care.(153,158) The parents interviewed recognised that these skills were not universal. Several mothers described themselves as “fortunate” or “lucky” that they had the ability to take on this role.(M10, M11, M15)

“I can see in the lives of lots of other children whose parents don’t have either the capacity or the energy to do that stuff, things are different... they get more complications.” (M15)

4.2.4 The extent of the technical expertise that families possess is poorly recognised by professionals

Although families carried out technical tasks and supported professionals with device care, professionals did not always acknowledge their expertise. One mother described how her son had been admitted for an operation to replace his gastrostomy tube. In order to confirm that the new tube was in the right place, a feed had to be given through the tube. None of the nursing staff on the ward were trained to use a gastrostomy, so his mother set up and administered the feed. Despite their lack of training, two nurses inspected her actions to ensure that it was carried out correctly.(M20)

“Two of them [nurses] had to watch me set it up... that was really quite funny, but I decided to let that go, because you just play the game cause you want to get out of there.” (M20)

The extent of the expertise that families acquired was seldom recognised by professionals. Some families had experience of caring for a child with an invasive device for many years without complication, only for the child to develop infections when the device was used by professionals.(M10, M11) One mother had been responsible for using her son’s Portacath at home and in hospital for over two years without complication. After he was admitted to hospital for medical care, the Portacath had been accessed repeatedly by nursing staff, and the device site had become infected. After discussions between the clinical team, the mother was informed that it was no longer appropriate for her to access the Portacath at home. She was not involved in the team discussions and no reason was given to her for the decision.(M10)

“I was really really insulted actually, because their argument was that from an infection risk, now that he’s immunosuppressed, it was too big an infection risk. And I said and argued that, you know, in all the months he’d been at home he’d never had an infection, it was only since his transplant, well since he was

admitted that there were infections, clearly my infection procedure was bang on, I'd done it right.”(M10)

Some parents had repeated assessments of their device care to make sure that the care they were providing was of a high enough standard. One mother described how the community nurse had come to her home and observed her giving medications through her daughter's central line. The mother's care was closely observed, and each stage of the procedure was marked by the nurse. The mother worked as a hospital nurse, and she was worried that the outcome of the assessment would impact on both her family life and her work. If she was not considered competent to use a central line, then her daughter would have to be admitted to hospital as there was no-one else available to care for her. The mother also felt that she would be unable to continue working.(M12)

“What would they do if I did fail? Because technically then I'm incompetent, I can't do my job.”(M12)

This mother was one of two parents in the study who were nurses by background.(M12, M15) These parents found that demonstrating their knowledge and expertise to professionals by using medical terminology and language gave them more legitimacy as experts in the care of their child.(253)

*“You just have to put in enough, even unnecessary jargon, to make them [healthcare professionals] believe that you know what you're talking about.”
(M15)*

The additional responsibility that was afforded to parents with clinical training meant that these families carried an additional burden. In one family, both parents were healthcare professionals. The mother felt that as a result, she and her husband made more clinical decisions about their son's care than they would otherwise have done. The ability to make decisions based on their clinical and personal expertise gave the family more independence than they would otherwise have had. However, it also meant that the burden on the family and responsibility for decision-making was increased.(M15)

“We're carrying all the responsibility over decisions which isn't very good for our mental health.”(M15)

Notwithstanding the reliance placed on families to carry out device care, professionals were sometimes unwilling to listen to their suggestions if it impacted on their own practice. Attempts by families to share their expertise with professionals were not always well received. One child had an extensive package of support at home, and several carers came to the home during the day and night. The mother was scrupulous about hand hygiene and device care. Unfortunately, she did not feel that the carers were as careful as she would like when cleaning device sites, or with regards to hand hygiene. She tried to explain her concerns to the carers, but these were disregarded.(M19)

“Some people feel like they know everything and you shouldn’t be telling them what to do.” (M19)

Eventually, the mother dispensed with the majority of the care package. She felt that it was safer to take the care on herself, thus ensuring that it was carried out to the standard she wished. Carers still visited the house once a day to assist her, but the mother was the only person who carried out the technical work of device care.

“That’s why I do everything myself now... I know that I’ve done it properly.” (M19)

Another mother described her frustration when explaining to healthcare professionals that her son had an infection. As a result of an immune deficiency, her son did not develop a fever in response to infection, and doctors would dismiss her concerns because her son did not react in a typical way.(M9)

“And I find it quite frustrating, because I’ll go to the doctor, and they’ll go well if he hasn’t got a fever and I’m like that doesn’t mean... it’s part of the immune deficiency is that you don’t get a fever...so many doctors don’t get that at all, and I’m going doesn’t mean he hasn’t got a chest infection because he hasn’t got a fever, because he’s been desperately ill before and not had a fever. I’ve had to become the expert on him.” (M9)

4.2.5 Children's contributions to device care

Children that I interviewed for this study often had a detailed understanding of the routines of device care and use; they demonstrated an appreciation of the different roles that each member of the network undertook, and how they, the child, formed a part of that network. The responsibility that each child took on varied depending on their individual circumstances.

Ensuring device safety during everyday activities was part of several children's responsibilities: children made sure that central line catheters were kept safe and replaced in "wiggly bags" so that the ends were protected.(C2, M1, F5) Children with devices were encouraged to participate in self-care by some professionals and to assist them when the device was used. One example of this was when a central line was used. The catheters protruded from the child's chest, and dangled down. To prevent the catheters from being pulled or damaged, the ends were usually stored in a small cloth bag around the child's neck. To use a central line, the catheters had to be removed from the bag and held securely. Some children took responsibility for doing this, often selecting which catheter was used and holding them while bloods were taken or medicines given.(M1, M2).

"They (nurses) can't just go to her lines and pull them out of the bag. She has to give them to them. She has to get them out. Like if a nurse grabs them she goes back into herself a bit ...she has to tell them which ones she wants the blood taken off. She controls." (M1)

When children were unable to have this level of control, it affected their confidence and their relationship with healthcare professionals was damaged.

Only certain named people were supposed to touch the device – these included their parents, school-teachers, and healthcare professionals. Children could touch the device as part of care, but not otherwise.

"I could touch it and stuff, but I don't play with it" (C7)

Although children were aware of the prohibition of touching the device, this was not always complied with. One boy disclosed that when he was bored, he fiddled with the ends of his central line.(C2)

Children themselves could alert parents and professionals to any problems with the device. Children with central lines could sometimes feel medications or feed enter their body, particularly if the liquid was cold. If a child told an adult that the process felt different, this alerted the professional to inspect the device more closely and look for any signs of damage or malfunction.(M2, F4, M11)

“Then he started getting, sort of, complaining that it was really hurting him, tender.” (F4)

Some children were very active, intervening, for example, when they were concerned that families and professionals had deviated from the usual standard of care.(M12, M14) One mother described how her daughter had been cared for by her grandparents on one occasion. The grandfather had started to give the medications through the girl’s gastrostomy, but had made a mistake. This error was immediately detected by the child and corrected.(M14) Another girl with a central line and gastrostomy had most of her care provided by her mother. When her mother was at work, her father had to give the medications and feeds through the central line. Her father was less experienced at using the central line than her mother and felt less confident. The girl recognised that he was developing these skills, and appreciated that his abilities were improving.(C12)

“He’s getting quite good at it” (C12)

This scrutiny was not confined to her family circle as the girl also commented on the care that she received from nursing staff.(M12)

“She’d be like that’s not how you do it. She has actually told the nurses before actually, did you do that right?” (M12)

Children felt that the insertion of the device resulted in a loss of control over their own bodies.(F1, M11, P9) As a result, many children tried to assert some control over the care and use of the device. Some children named the device after their favourite cartoon

characters (e.g. central lines with two catheters were often called ‘Peppa and George’ or ‘Anna and Elsa’ from the Disney film Frozen). Children also tried to control who had access to the device. By only allowing a preferred parent to participate in the daily care of the devices (e.g. change dressings or clean the device site), children tried to regain some semblance of control over their own bodies.(M1, M2, M8, M9, M17)

“Just recently she has asked you [father] to change the plaster”(M1) “I think one of the things is to have a bit of control over the situation.” (F1)

As children developed more experience with a device, they became more competent with device care. This offered them more control over their own care by helping to give medications through their device (M14) or by adjusting feed pumps when alarms are triggered (M11). Parents were conscious that this sense of control was very important to children. They described the importance of children taking charge of device care themselves, especially as the child became older and took more responsibility for their own health.(M11, M14, M17)

“He’s actually sorting it out himself. So, it’s good for his confidence I think, not always being entirely dependent on people.” (M11)

“She takes ownership of her button so she’ll say to me, no, I’m doing it. So I’ll lock on the syringe for her, and then she’ll unclamp it, dispense it in.” (M14)

Over time, some children developed expertise in managing tasks of everyday living such as washing and bathing while maintaining device safety. Children learned how to navigate their world with the device in place, in a way that allowed them to maintain some independence. This expertise developed over time, sometimes after periods of trial and error.(C12)

“We found nowadays if I have a shower, I can do it connected because I can put my bags on the side in the bathroom I can stand in the shower, and if I’m just careful where I put my line it doesn’t get wet... It’s taken about three years.” (C12)

Children were able to regain some of the autonomy that the device restricted by carrying out device care themselves (246), and integrating this care into their everyday lives.

Not all children were able to carry out device care. Some children had learning difficulties which meant that their ability to carry out device care themselves was limited. Parents supported their child's involvement in device care, but had to evaluate whether or not this was safe.

"Cleaning, no, he wouldn't do that either... he wouldn't be able to think to do it"
(M9)

Children and families worked in partnership to optimise device care, negotiating options to minimise the impact of infection. One boy had problems with over-granulation at the site of his gastrostomy, and had struggled with recurrent infections. As a result, using a gastrostomy with a "button" attachment was painful for him, as the button sat close to the skin and pressed on the sore area. The boy and his mother agreed that he could try with a tube instead of the button. As time went on, his mother felt that the gastrostomy tube was making the problem worse, and they agreed to go back to the button.(M9)

"All the stuff that was leaking out was sitting underneath it [gastrostomy tube], so it was just getting sorer and sorer. So I managed to persuade him to go back to the button." (M9)

4.3 The emotional impact of device insertion and care on children and families

The insertion of the device and the subsequent burden of care that fell on families had a significant emotional impact on the child and their family. The device and the care that it required made the child different from their peers, affecting their relationship with family, friends, and strangers. Families became isolated because of the demands of the device, further adding to the relentless emotional burden which device care imposed.

4.3.1 Children and families recognise that the device makes the child different

The device was a physical breach of the child's body at a time when physical changes were already taking place.(254) The device created many aspects of difference, both

physical and social. In their interactions with others, children realised that they were treated differently and stigmatised from their peers because of the device.(252)

“It singles him out as being different and the one thing he doesn’t want to be, or any kid doesn’t want to be, is different.” (M8)

From a young age, children showed an awareness that having a device made them different from their peers.(C1, F4, M8, M10, M11, M12, M14, M17, M18) One child temporarily stopped using his arm after his Portacath was inserted, instead holding it across his body (F4); another refused to move his arm or neck at all for the first few weeks (M8).

Children developed a gradual realisation that they were different from other children because of their device.(F4, M14) This reflected their growing awareness of themselves as individuals.(255) Two parents described how their children had initially thought that all children had devices. Both children had had their devices inserted when they were very young. As they learned more about themselves and their bodies, they realised that they were different.(F4, M14) One father had two sons with Portacaths and a daughter with no device. He described how his youngest son had initially thought that Portacaths were associated with gender, and linked the Portacath with other physical differences between boys and girls.(F4)

“Because he’s got the idea we see it like he’s only just starting to realise that not everyone has it and then for a bit he had it because his brother’s got CF [cystic fibrosis] and his sister hasn’t, so obviously boys have CF and girls don’t, so boys have ports and wriggly worms and go to hospital and girls don’t, maybe that’s what happens.” (F4)

As children grew older, they compared themselves to other children and adults. The father went on to explain that he believed his son now thought that a Portacath was something that children had, but not adults.(F4)

“But then he sees me not doing it [using Portacath] so then it’s well maybe adults don’t do it but children do.”(F4)

Another mother confirmed the idea that children gradually realised they were different. This mother had a daughter with a gastrostomy. After discussion with her daughter, the mother realised that her daughter thought that all children had a gastrostomy when they were little, and that having the gastrostomy removed was a symbol of growing up.(M14)

“She thought all children had one, and that they just got removed at a certain point.” (M14)

These examples demonstrate that it was only by comparing themselves to other children who shared similar characteristics (such as age or gender) that children with devices realised that they were different from their peers. This is an example of the bodywork that children with invasive devices undertake to establish their sense of self.(255-257) As the device remained in place for longer, it became more apparent to the children and families that they were different from other children. The realisation meant that some children found the physical appearance of their device very upsetting. They became very concerned to prevent others to seeing the device, and kept it hidden under clothing.(C1, F4, M8) Children could become very distressed if they felt that their device was ‘on show’ and visible. This occurred across different situations, and with different groups of people.

“I picked him up and carried him back into the room without a top on and he got so upset ... I didn’t twig until a bit later that day... I think I probably took him without a t-shirt on and just he had this thought that people would be like looking at him.” (F4)

4.3.2 The child’s relationships with others

Children made attempts to hide the device from their family and peers in an attempt to conceal their difference – a phenomenon described as “passing as normal”.(252) Children’s self-consciousness about their device meant that they were cautious of letting relatives seeing the device. This included siblings, grandparents, and even parents who would otherwise be closely involved in their daily care. One parent would perform most of the daily care, and the other parent would only reluctantly be “allowed” to participate

in device care (M1), limiting who could support the family in caring for the child, and affecting the family dynamics.

Even if the device was hidden under clothing, some children became very concerned that it would be seen or “detected” by others.(M8) Children’s awareness that they were different led them to isolate themselves from their peers, even when they were to all appearances integrated into their schools and local communities. One girl, aged 2 years at the time, would not allow her friends at nursery to sit next to her on the side where the device was placed.(M1)

“There would always be a spare chair and she would always put her chair that way around... and when she left the empty chair they didn’t fill it.” (M1)

Peers at school were often curious about the device and its implications for the child.(M11) Other children frequently asked questions either of the child, or to their support worker or parent. Negative responses affected children’s interactions with their peers, and could lead to them concealing the device. Children were also fearful of the responses of others when they viewed the device: one child felt that it would make him a target for bullies.(M8) Over time, school friends usually became accustomed to the device, and accepted it as part of the child.(M11) Once children had become integrated into their peer group, and had faced the initial curiosity of their class mates, they experienced frequent changes which threatened their acceptance by the group. Moving into a new peer group meant that children faced more curiosity about their device, at a time when they were trying to fit in.(M11) Changes in care provision between primary and secondary school also disrupted children’s integration into their peer group.(M12) At periods of transition, such as when changing schools, children expressed uncertainty that they would be accepted by their peer group if they had a device in place, as it would make them different.

“It [central line] will go out when... I go to school... the people don’t have wiggles there.” (C1)

Schools attempted to support children by providing separate changing facilities or toilets for them. However, this risked exacerbating the feeling of difference between the child and their peers.(M8, M17) Concerns about the child’s safety could lead to them

being separated from their peer group in lessons, and in break periods, thus making the differences more apparent.(M12)

Some children did not accept that they were different, refusing to use separate facilities or to acknowledge that they had a device at all, compromising their ability to care for themselves and the device safely.(M8, M17) The following example describes how stigma affects device care in children.(252)

“They gave her a private toilet for all her stuff... and she refuses to go there because she doesn’t want anyone to think that she’s ill or different... she’s bad about doing things in school.” (M17)

The child’s relationships with others was also affected by the device. The mother in this family feared that their family would suffer from the stigma in their community if it became known that their child had a medical condition that required a device. As a result, the device was hidden from members of their community, and the care of the device was also concealed.(M17)

“We don’t want everyone knowing everything, so the less people know the better...I suppose the stigma is very big in our community.” (M17)

The fear of stigma meant that the family concealed the device from professionals that could have offered support to the child. She received no support from school staff, most of whom were unaware that she had a device. The family had considered the benefits of having school support, including the possibility of a learning support assistant who could have been trained to help their daughter with gastrostomy care. After consideration, they decided that there would be little additional benefit. The mother expressed concerns that the support would not be available when it was required as either the member of staff would not be present, or that they would be unable to deal with the stress of managing a gastrostomy.(M17)

“The person who’s going to be trained is never going to be available if it [gastrostomy] does ever come out so we didn’t bother... they’d all be freaked out and they wouldn’t want to do it.” (M17)

During the school day, the child took responsibility for ensuring that the colostomy was covered with a bag and that no contents could leak onto the gastrostomy. The child was also able to administer her own medications and feeds through the gastrostomy. (M17)

“[child] can do it herself, so she connect and disconnects, I give her the syringes and medicines in the morning and she’ll just give them herself and flush it herself.” (M17)

This aspect of self-care was not supported by any professionals. The mother had taken the decision to train her daughter to carry out her own care to protect her, and her family, from the impact of being different. By controlling the flow of information about the child’s device, the mother tried to protect her from the stigma of having a device.(252)

4.3.3 Dealing with the public adds to the feeling of difference

The experience of stigma was also an issue outside of the child’s circle. In some cases, “passing as normal” (252) was not an option, as children needed to have feeds or to have suction from their tracheostomy in public. Tracheostomies were usually visible as the neck was exposed, leaving the device and the tapes which secured it on public view. Although other devices, such as gastrostomies and central lines were usually hidden beneath clothing, the shape of the device could be revealed beneath clothing. Gastrostomy contents could leak, seeping through onto clothes. Suctioning the tracheostomy was noisy and involved the removal of bodily fluids in a public space. Such a procedure made others feel uncomfortable.(251) Using the device made their differences from other children very apparent (258); families found that they were stared at when carrying out cares in public, especially if this produced a lot of noise or involved feeds. Some family members found this very difficult to deal with, and felt embarrassed by the device and the care that was required.

“But I think [father] still does, find it a bit, wanting to explain, and if he doesn’t then he’ll go into almost very obnoxious mode...I don’t think he’s embarrassed of him, I just mean he’s embarrassed of it.” (M6)

*“If they’ve [siblings] seen people are staring they get quite annoyed about it.”
(M14)*

Families responded in different ways to this interest from strangers. Whereas some families felt very protective towards their child and tried to shield them from the attention, others felt that they had no choice but to carry out device cares in the public arena, regardless of the reaction from others. This was a difficult transition for families to make, and it took time for them to feel comfortable with carrying out cares in public.(M6)

“We’ve learnt to just be a bit more brazen about it and not care, but at first I found that really difficult” (M6)

Families often had to deal with comments from strangers about their child’s health, or were asked questions about their care and medical conditions. Occasionally, families had to deal with more direct involvement from strangers.

“His feeding tube was dangling out from underneath his T-shirt, and this (...) came along, went dingdong, what’s this for then? Pulled it” (M10)

These intrusions by uninvited strangers are one example of how the integrity of the family unit is compromised when a child has an invasive device. Normal family life is enclosed and protected; how much is disclosed to the outside world is, in the main, at the discretion of the family. There are very few instances in which this protective barrier is breached. Having a device breached a physical boundary of the child’s body; it also breached the normal family limits in society.(259)

4.3.4 Isolation

The demands of device care meant that children and families could become isolated from their peers. Children needed specialised care in order to maintain the device safely. Parents were trained to care for their child and the device before discharge from hospital. For some devices such as Portacaths, the additional everyday care was limited, thus the training was brief. Other devices, such as tracheostomies and gastrostomies, required ongoing care from families. The training for these devices took weeks and

sometimes months before professionals deemed parents competent to care for the child at home. Throughout this time, children were in hospital with their parents, away from the rest of their family.(M6)

Once out of hospital, children were isolated from other children. Activities that would ordinarily be shared time between siblings, such as sharing a bath, were no longer possible.(M1) Some children could not attend nursery or school because staff had not received adequate training.(M3)

“She was already in the special needs nursery; she couldn’t go to either because they weren’t trained.” (M3)

Participation in normal childhood leisure activities was limited and could only take place when a trained adult was present. As a result, children struggled to spend time with friends outside of their family circle.(M12, M14)

“She’s just at the age when people are starting to ask for play dates, and so far we’ve had to say no.” (M14)

Difficulties in organising reliable and suitable care limited parents’ return to work, even when their child was medically well and able to attend school full-time.(M6) Where formal respite care was available, it was often not appropriate for the child’s needs. Families often remained with their child in school or in respite care in order to reassure themselves that their child was safe. This came at the cost that there was no “time-off” for families.(M12, M13)

“I mean generally she doesn’t go anywhere without me, so I tend to keep an eye on it and know what’s happening.” (M13)

The lack of freedom became more apparent to parents as their child grew older. Families had anticipated a time when the children would be more independent, and the parents could have more time to themselves. The development did not happen with children with invasive devices.

“I suppose that’s the biggest, biggest thing we notice now, as the kids have got older, that everyone else is off doing things, and we’re still kind of tied to, not quite as free.” (M12)

Thus families were worn down by the relentless nature of the care of a child with an invasive device. Parents could not relax their vigilance when they took part in social activities (M10), and opportunities to meet other parents were limited. When families did go out, the need to provide care for the child meant that parents had limited opportunities to interact with other families. Parents had little in common with other families.(M10)

“I was sat there in this room with all these other mums yattering on about nappies... and I didn’t feel the need to talk to anyone, and I realised just how isolated and lonely I was” (M10)

4.3.5 Relentless nature of device care

Parents took on the bulk of the daily care of the device: they changed bags that held central line catheters (“wiggly bags”), replaced dressings, and changed gastrostomy “buttons”.(C1, C2) This technical work was both highly skilled and time-consuming for families.(M12, M15)

“If you break it down it takes up an awful lot of the day, you know, unplugging him, turning machines off, unscrewing things, putting meds in, flushing it, it adds up to being quite a constant thing” (M12)

In addition to the physical work, families had to continually plan ahead and think about the device. The responsibility for organising and coordinating the different aspects of the child’s care fell upon the parents. Parents were responsible for ordering feeds, medication, and equipment, and for making sure that they did not run out.(M10, M11, M12, M13, M17) Supplies came from a number of different organisations, and were delivered at different times and in varying quantities. Families could not simply order supplies for a month as some organisations only supplied weekly or fortnightly deliveries.(M12, M17) Parents also had to keep track of supplies outside the family

home. One girl had bloods taken from her Portacath by community nurses who visited the school. Her mother kept a supply of equipment at the school for the nurses to use, and replenished this when needed. Yet keeping track of what equipment needed replacing proved challenging as the community nurses did not keep a record of what had been used and therefore needed replacing.(M13) Rather than professionals informing families of what equipment needed to be ordered, families had to explore what had been used and replace their stores accordingly.(M13, M14)

“Keeping on top of the equipment can be a challenge, because if they don’t do it here and I don’t always see when they’ve run out.” (M13)

Coordinating appointments and transmitting information between different members of the team was also down to parents.(F4) Some parents also organised investigations, chased the results, and prompted changes in their child’s management as a result.(M13, M17) One family organised regular blood tests for their daughter: the mother took blood tests from her daughter’s central line which the father then drove on a two-hour round trip to a specialist hospital to be tested.(M12)

As a result, there was an additional cognitive burden placed on families to organise their child’s care. Parents were exhausted by the physical and cognitive demands of caring for a child with an invasive device.(M6, F7, M8, M10, M11, M12, M15)

“The actual days organising and trying to sort of, sort everything out is actually harder than physically caring.” (M12)

Families could not allow themselves to relax or forget about device care: to do so would put the child at risk.(M6, M10, M15) The fear of significant medical harm; of causing pain; of knowing that a child with a device was different from their peers was never-ending. This work of managing emotions – the emotional labour – was in addition to the physical and cognitive work that came with caring for a child with an invasive device.(260) Families were always on the lookout for potential risks to their child and did not feel that they could relax. The unremitting emotional burden added to the difficulties that families faced, reducing their resilience and limiting their ability to cope with new challenges.

“Just the 24-hour thing, 24-hour just gets him [father] down” (M6)

*“I have just burnt out from keeping a normal day life going and everything else”
(M8)*

The relentless nature of the care that the child with an invasive device required was different from the demands placed on parents by their other children. One mother explained that with her other child, there were shortcuts and adaptations which could be made which would still meet their needs and reduce the burden on her. Such adaptations were not possible with her son with a gastrostomy as the level of care he required could not be reduced. “Quiet” evenings, where the family could eat takeaway and relax were not an option if the child had an invasive device.(M15)

“You can’t be lazy with stuff”(M15)

The physical and mental demands of providing unceasing nursing care for a child exacerbated the emotional strain that families were under.(M8, M10)

“It was more absolute exhaustion, in some ways a posttraumatic stress... we were just on tenterhooks that he was going to die... constant pressure on us. And the lack of sleep as well, because even with the respite care, when he was needing 24/7 care, we didn’t get seven nights a week respite care.” (M10)

Although families accepted the physical work of caring for their child, the inescapable emotional cost was particularly difficult to bear. In comparison to the emotional labour required, the medical implications of their child’s condition and device care seemed more manageable for some.

4.3.6 The impact of device care on relationships with other family members

Siblings were also affected by the care needs of the child with a device. Prolonged hospital admissions meant that siblings could be separated from the family unit for long periods of time.(M6) Families worked hard to try and make sure that siblings could still attend clubs and after-school activities, seeking to continue normal family life, even though this carried a considerable workload.(162) A child with a device could not be

left unattended or with a carer who was not trained in the care of the device. Taking other members of the family to activities meant that the child with the device had to accompany them.(M3, M6, M12) These journeys were exhausting for the child with the device, and their family. Siblings were also affected by the child's state of health: if the child was unwell, then normal routines of after-school activities would be cancelled.(M3, M12) Fitting these journeys around every day routines of washing and bedtime was particularly challenging as children were tired.(M3)

Siblings developed an awareness of the care needs of their sibling with the device. Some siblings helped their parents carry out device care, by fetching equipment or alerting their parent when there was a problem with the device.(M3, M10) Although they did on occasion carry out cares, such as removing a blocked tracheostomy in an emergency, siblings received no training or support in the care of the device.(M3, M12)

"I mean, I've had to get [brother] to do things... she's coughing and she's got, like – she's blocked here, she can't breathe. She can't breathe up here. And we were on the M5... So we had to get [brother] to, like, undo his seatbelt – 'cause he couldn't reach across to her, so he had to undo his seatbelt while we're, like, on the motorway." (M3)

The distress that children experienced during device care impacted on their siblings. One mother described how her older boys were very protective of their younger sister who had a gastrostomy. The boys become very distressed during device care which their sister found painful, and had to leave the house when this care took place.(M14). Conversely, some siblings did not appreciate that the device could cause pain, and took part in violent play which could damage the device. As a result, parents had to intervene and restrict the interaction between siblings.(M9)

"I'm always like that, remember your brother's got a tube in!" (M9)

The restrictions placed on children with invasive devices impacted on the rest of family. One boy with a central line was very distressed that he could no longer go swimming. As a result, the family decided that his younger sister should also stop swimming.(M8) Care of the device disrupted the relationship between the siblings.

“He wouldn’t even let his sister go swimming because it wasn’t fair if he couldn’t go as well.” (M8)

Extended family, such as grandparents, could also be trained in the use of the device, enabling them to care for the child and allowing the parents valuable respite time which they could spend with each other or with other children.(M3) Although welcomed by parents, the reliance on the wider family network further altered the dynamics in the family. Families were aware of the strain of caring for a child with an invasive device, and were reluctant to impose this on others.(M3)

“You know, she [aunt] works full time. I mean, she can have [Name 1] for a couple of hours. She’s done tube changes and she’s done suction, but, you know, she’s in [Place 10] and she’s got her own life. You know, she’s got her own job, so....”(M3)

Not all family members felt able to care for a child with an invasive device. One mother explained that her family and that of her husband lived close by. The grandparents did not feel able to care for her daughter who required gastrostomy feeds and medications giving.(M18)

“Mine and [husband]’s parents... they’re brilliant with the others, but never managed to get over the hoisting and gastrostomies.” (M18)

Parents were also concerned that other family members did not share their expertise in caring for the device, and would not recognise problems if they arose.(M16)

“You worry if you leave them with someone else... it’s a lot to take in, keeping it all safe.” (M16)

The wider family were impacted by the insertion of a device, even if they had no direct role in caring for the child.

4.3.7 Children choosing to disengage from device care

Some children struggled to adjust to living with a device. The strategies that they used to cope with device insertion affected their participation in device care. Some children coped with their device by refusing to interact with health care professionals or to take responsibility for device care. This was a deliberate, intentional choice to disengage from what was happening to them and their bodies. Some children did not want to take any more responsibility. One boy described how he *“just let them [community nurses] get on with it”* when his central line was accessed for bloods in his home.(C2) Parents were very aware that their children would actively choose to distance themselves from situations that they found distressing.(M2, M8, M10)

“He has this wonderful capacity to shut down and you do not exist.” (M10)

Observations showed children’s interactions during device care and the ways in which they demonstrated withdrawal. In one visit, a nurse came to take blood samples from a child with a central line – child 2. The child and nurse talked quite comfortably while she prepared her equipment, but this changed as she began the process of taking blood samples. The child cooperated with the process by taking the lines out of the cotton bag around his neck, and held the end while the nurse took the blood samples. But he stopped answering her questions and refused to make eye contact during this time. His posture changed and his shoulders rounded. Afterwards, I asked him about the visit: *“I would normally sit here and ignore them” (C2)*. Although the child performed the tasks expected of him with regards to the device, his body language showed that he was distancing in order to cope with the situation.

Another experience reinforced this idea that children were distancing themselves from the device. While conducting an interview with a father, the child (child 4) seemed to be playing happily and walking around the room. As the interview progressed, I noticed that every time we mentioned the Portacath, his demeanour changed. Several times, he turned his back to us and stopped his play for a few seconds, before carrying on with his game. On one occasion, he walked away from us to the entrance of the room and stood in the doorway for a few minutes before returning. I wanted to check with his father that this was different for him, rather than his usual pattern of play

IT'S NOT BECAUSE WE'RE TALKING ABOUT IT? (Researcher)

"Maybe a bit, I'm not sure, just because of the way he walked off was quite quiet rather than telling me I'm going, so maybe." (F4)

This was more than passivity; rather, it demonstrated children's agency by choosing to distance themselves from a situation over which they could exert no other control. They demonstrated this through their body language: by turning their backs when the device was discussed; or by refusing to interact socially when the device was being used. Children recognised that the situation was beyond their control, and that expressing their views would have little impact on the outcome. Despite this, they still took the opportunity to act (even if through a negative act such as distancing themselves).(261,262) This distancing could begin even before the device was inserted. One play specialist described how she carried out role-play with children to prepare them for device insertion. Her aim was to prepare the children, but sometimes had to turn her attention to the parents when the children did not want to participate.(P6)

"Some of them refuse to look, don't want anything to do with what I'm saying, so a lot of the preparation is directed at the parents so that then they can talk them through it as it happens." (P6)

The reasons for distancing were explored by one child who explained that she did not feel that she would ever be able to deliver her own device care. This girl gave the example that she would not be able to connect the PN to her central line by herself. She would rather not have to have a device in the first place, and felt that it was enough to cope with the consequences of her medical condition without adding in additional responsibilities.(C12)

"I really don't think I'm ever going to be able to do my own PN [parenteral nutrition]... If I didn't have to have PN then I wouldn't have it... I've got enough medical stuff, I don't really want to." (C12)

Thus for some children, refusing to engage with device care was one way of coping with the psychological burden of the device and the underlying disease.

4.4 Device care outside the family circle: school attendance

The data I have presented thus far look at how device care is carried out within the confines of the family circle. However, children are not exclusively cared for by family members. In this section, I explore how care of the child with an invasive device is conducted outside the family circle, using school as an example. Most children with an invasive device attended school when they were well enough to do so – only two children (child 10 and child 19) did not attend school regularly.

4.4.1 Who is involved?

Care of the child in school depended on the needs of the child and their device. Teachers and teaching assistants provided children with support during the school day to ensure that children could participate in school activities safely. Protective clothing meant that children could play with sand and water without getting the device dirty.(M1) Some school-workers were more directly involved with the device. This was particularly true for children with gastrostomies as gastrostomy feeds and medications were often given by teaching assistants.(C9, M20, P7) Other children received dedicated one-to-one support from trained carers to carry out tracheostomy care and gastrostomy feeds.(M3, M6)

Schools were often apprehensive about caring for a child with an invasive device. Much of the support for school staff came from community and specialist nurses. Nurses visited schools and nurseries to teach staff how to care for a child with a device, and created care plans with the school in case of any difficulty.(M1, M2, M14) The nurses also explained to the child's classmates what the device entailed and why it was needed, helping children to integrate back into their classroom.(F4, M8) The support from community nurses helped school staff, and parents, feel more confident about their child's return to school.(F1) Although these sessions were meant to support the links between the child, community, and healthcare, parents were not invited to take part. As a result, parents were not always aware of what information the school and their child's classmates had received.(F4)

“The CF nurses came out and had a talk with all the staff, not with the children, we weren't invited to those meetings, so I don't know exactly what they said.”

(F4)

Despite this support, some parents felt that schools struggled to care for a child with an invasive device.(M2, M11) When a school had previous experience of caring for a child with an invasive device, they were more confident that they could meet their needs. As a result, parents felt more confident about allowing their child in school and trusted that the school would be able to care for them safely.(F1, M14)

“The head teacher mentioned they have had children with [central] lines so that is good and very proactive really and understanding.” (F1)

Some children, such as children 3, 6, 9, 13, 15, 16, and 18, were in schools for children with special needs – their families felt that they received more support as a result. The teaching staff were more accustomed to children with invasive devices, and there was more nursing care available.(M9, M13, M16)

“I dread to think how it would have been if he was in mainstream” (M9)

Children were able to report to school staff if there were any concerns about the device. School nurses could assess the device to see if there were any signs of infection.(M9, M11) However, school nurses were not always available in mainstream schools. As a result, parents had to provide additional support to the school.

4.4.2 Families working with schools to support their child's attendance

Parents sometimes accompanied their children to school to provide additional reassurance for school staff.(M2, M12) If the parent was not physically present at all times, then they were often called to address any concerns that the school had about the device.(M2, M11, M13) Families worked with schools to ensure that children were able to participate in school activities when it was felt safe to do so.(M11) Despite precautions, everyday activities could cause pain to the child if the device was hit.(C2, F4) Parents were contacted by schools if there had been any problems with the device (F4, M8, M13), and some parents spent the entire day at the school.(M2, M12, M14)

“I think the teachers also freak out a bit. I think they are very worried. I mean he has been hit in the chest with a football a few times and they have rung up saying...because he panics, they panic and we have had to come running to the school to check it out.” (M8)

Although children had detailed care plans in place, and close links with community healthcare professionals, parents had to ensure that these plans were carried out properly.(M6, M8, M14) Notwithstanding the training that schools had received, staff did not always appreciate how much support children with invasive devices needed. Families had to ensure that care was delivered safely, and that the staff were fully aware of the child’s needs.(M6, M8) Schools contacted parents to clarify the care plans that they had received from the community nursing teams, and for their own reassurance.(M8, M14)

“I basically spent three weeks going in and out of school explaining to people that it was fine and he knew what to do with it.” (M8)

In some cases, parents took responsibility for training teachers and support workers to give feeds or medications through a gastrostomy.(M9, M14) Although there was support from the community nursing team, one mother used a step-wise approach to make sure that the teaching staff were competent to use her daughter’s device.(M14)

“The first week of term I went in every single day... for the first three days I did everything, they watched. And then after that I made up the medications and they put them through the tube.”(M14)

If families were not able to oversee the care of the child themselves, they had to rely on professionals to care for the child. Some families used the direct payments system to employ trained carers to accompany their child to school. Families relied on these carers to ensure that the child was safe, and that device care was carried out safely.(M6)

“If I didn’t have a one-to-one carer, those questions, I think things might be overlooked. I mean having an outside agency is great, because I’ve not got someone who’s tied to the school... I get to hear what happens because he

[support worker]’s got no allegiance to the school, if he’s concerned about something he’ll tell me so it’s quite nice that way, because [child] doesn’t have a voice, does he, he can’t talk, I need somebody to be stood up for him.” (M6)

Families used their skills as managers of their child’s care to ensure that they received appropriate care outside the home, as well as within it.(153)

4.4.3 Managing challenges in the care of the device

Although families and community nurses worked closely with schools to facilitate the child’s care, challenges remained.

Negotiating appropriate places for device care could prove difficult. When using a central line to take bloods or give medications it was essential that the carer had access to running water to clean their hands. This could prove difficult in schools, where there was limited space available. Few schools had dedicated medical rooms with the required facilities. As a result, device care was carried out in staff toilet or kitchen areas. Some families felt that the staff in schools did not really appreciate how serious a device-related infection could be, as teachers had suggested the children’s toilet as a suitable area for device care.(M11)

“One suggestion was that we did it in the toilet, this is when he had Hickman [central] line. Like no, no, absolutely not!” (M11)

Some children were restricted from participating in activities such as sports at school, even though their parents and healthcare professionals felt it was low risk.(M13) In other cases, children were prevented from taking part in school activities because the school had not made allowance for the care that the child required. One mother described how her son’s school had offered him a place on a trip away over five days. Her son attended a school for children with special needs, and had a one-to-one carer who was trained in gastrostomy and tracheostomy care. The school felt that it would be adequate if staff members from the school stayed with the boy. The mother had to explain to the school that in order for him to attend, her son would require 24 hour, one-

to-one care from specially trained carers throughout the duration of the trip. The school felt that they could not accommodate his needs and withdrew the place on the trip.(M6)

Despite reaching agreement with families and health professionals about the care of the child, some schools came over time to perceive that they could not cope with the care of the child. One girl who had been in a mainstream school placement had been asked to leave after developing complications with her Portacath. Before starting school, her mother and community team had outlined a care plan with the school, including any potential complications. Unfortunately, when one of these complications materialised, the school felt that they could not manage. She transferred to a special school where the staff were accustomed to dealing with children with additional needs.(M13)

“She’s transferring to special fulltime now, and they’re used to dealing with lines, oxygen, tubes, and so they’re not bothered at all.”(M13)

For some children, the demands of the device meant that they could no longer attend school with their peers. One girl had a care plan agreed with the school which meant that she could attend while using her central line to receive intravenous nutrition. However, this agreement was later over-turned by the school and the family was told that the child could no longer attend school.(M12)

“They let her go to school originally on PN, and there was some, what do they call it? Health and safety meeting, and they decided they couldn’t have her in school on her PN!” (M12)

Coordinating the different agencies involved was challenging, and parents struggled to ensure that their children’s needs were addressed, resulting in large burdens on families. One child had a gastrostomy, tracheostomy, and Portacath inserted throughout. His medical condition left him too tired to manage more than a few hours a week of nursery and he attended hospital several times a week. In addition, his devices meant that specialist support staff would have to be available at school. After struggling to convey these challenges to the education authorities, his mother decided that it would be less disruptive to home-school him.(M10) This example demonstrates how some attempts at

normalisation, despite families' best efforts, can increase the disruption to the child's normal life rather than enhancing it.(244)

4.5 Summary

In this chapter I have explored how families experienced device insertion, and the impact that the device had on their everyday lives. The device could support the child to live a normal life, but also imposed burdens which threatened this normality. Families managed these conflicting demands by taking on additional work themselves to promote their child's normal life. Such attempts were only partly successful, and the device remained an object which made the child different from their peers and exposed them to stigma.

Families in this study experienced device insertion as a stressful event which indicated that their child's illness had progressed to a stage where they required the device for their wellbeing. Whether the procedure occurred as a gradual progression in the disease or a sudden event, device insertion was distressing for children and families. Families recognised that the care of the device would carry additional burdens, including the risk of serious infection.

Despite these concerns, some families felt that the device was also a means of supporting the child to live a normal life. Parents described how the device could reduce interruptions to their routine as children no longer needed to attend hospital to have blood tests taken or feeding tubes replaced. For others, the device was a way of ensuring that the child could live at home safely rather than in the hospital. As such the device was viewed by families as a means of facilitating the child's normal life.

However, the device and ongoing care that resulted also posed threats to the child's normal life. Caring for the device meant families had to take on time-consuming and technically challenging tasks which had to be incorporated in the everyday life of the child and wider family. Families recognised that the device was a complex piece of medical equipment and were anxious about the care that they provided in case harm resulted to the child. These burdens were amplified when children attempted to participate in normal childhood activities, such as playing with friends or going on holiday. Rather than completely restrict children's activities, families took on additional

burdens to minimise the impact that the device had on the child and their pursuit of a normal life.

Notwithstanding the significant efforts of families to pursue a form of normality, children and families recognised that such efforts could only be partially successful. The presence of the device made the child different from the peers – something which children became increasingly aware of as they grew older and their social circle expanded. The awareness that they were made different by the device affected children's interactions with their family, friends, and wider social group. Both the device and the care required to maintain it exposed the child as different, despite efforts to conceal the difference. The resultant stigma affected how children undertook device care.

The demands of device care meant that ordinary progressions in the child's life were also affected – further emphasising that the device made the child different. Children were dependent on family members for assistance with everyday tasks such as washing which they might otherwise have carried out with minimal supervision. Interactions with peers such as playdates and sleepovers were restricted as children needed to have a trained carer with them to help care for the device. These requirements impacted on the wider family: siblings struggled to participate in after-school events and parents were unable to leave the child to go to work or socialise. Even when children were cared for away from the family home, for example at school, families still found themselves supporting the care of the child.

Thus while device insertion was seen by families as a necessary procedure which could enable children to live a more normal life at home, the resultant demands imposed a significant burden on families. These burdens were exacerbated by the demands of IPC, as I explore in Chapter 5.

5 Experiences of device-related infection

In this chapter I describe how children and families experience different types of device-related infection, the work families did to manage infection risk, and the consequences that these practices have on everyday family life. Families were aware of the risk of device-related infection, although device-related infections are relatively rare events. Only seven of the families involved in this study had experienced device-related infection themselves; other families had heard about the impact of infection through professionals and peers. In contrast, most of the professionals in the sample (16/20) had experience of caring for children with device-related infections. As such, while data included in this chapter predominately comes from family interviews, I supplement this analysis using the insights from professional participants where professionals were able to provide additional or richer insights into how families responded when a child developed a device-related infection. This included contributions from P8, a founder of support group for parents of children with cancer, who was able to reflect on her own experience of a child with an invasive device, along with the experiences of other parents she had worked to support. I explore the impact of device-related infection on professionals in greater depth in section 6.2.

Before describing how children and families experienced device-related infection, I explain the different types of infection that families described. I use the terms “device-site infections” and central line bloodstream infections (CLABSIs) to describe two distinct forms of device-related infections. Both device-site and bloodstream infections had a significant impact on the quality of life of children and families but were viewed differently by families.

Device-site infections develop in the skin and soft-tissue around the wound formed by the device, as a result of pressure sores from tapes used to secure a tracheostomy, or from skin breakdown from dressing changes.(43,84,85,89) Such infections may also develop as a consequence of over-granulation leading to skin breakdown.(40,83,84,90) Device-site infections are associated with tracheostomy and gastrostomy sites, but were also experienced by children with Portacaths in this study. These infections were confined to the device site and were not considered life-threatening. Treatment of

device-site infections included ointments and dressings, and children were usually cared for at home.

Bloodstream infections were viewed differently by families. Central-lines and Portacaths provide a direct conduit for bacteria to enter the blood-stream, resulting in CLABSIs. Bacteria spread around the body through the blood stream, multiplying rapidly, causing serious and potentially life-threatening infections.(67,91,92) Children become unwell very quickly. A high temperature can be a sign of CLABSI in a child even if there are no other worrying features.(93,94) Families are advised by professionals that a child with a central line or Portacath can deteriorate rapidly, and to seek urgent medical attention if their child develops a fever. (See **Table 1.2.** Chapter 1 for further details of the infections associated with invasive devices in children).

5.1 Medical treatment increases the risk of device-related infection

In addition to the everyday risks described in chapter 4, children were also at risk of infection resulting from medical treatments. In this section, I describe how therapies intended to keep the child healthy could themselves increase the risk of device-related infection.

5.1.1 Device use increases the risk of infection

Using the device was associated with other possible sites of infection as device adjuncts damaged the child's skin, leaving it open to the outside world. One example was in the use of tracheostomies. To ensure that the tracheostomy tube was firmly secured, narrow cotton tapes were tied to the tube and secured around the child's neck. The tapes had to fit snugly around the child's neck to make sure that the tracheostomy tube did not fall out accidentally. As the child moved their head, the tapes rubbed against the skin on their neck. Friction from the tapes could result in pressure sores, leading to skin breakdown which then became infected.(M19) Other measures designed to protect the device from infection could sometimes make the child more susceptible. Some children had sensitive skin which reacted to the waterproof dressings used to cover central lines and Portacath needles. The dressings were changed frequently. As the dressings were removed, the skin underneath appeared red and inflamed. Over time, repeated exposure

to the dressings damaged the skin and left a route for infection to enter the body.(C12, M13, P1)

“I think if you are going to get breakdown of the skin and you are going to get an infection in that way.” (P1)

Skin breakdown was a particular concern for children who had Portacaths. In order to use the Portacath, a needle was inserted through the skin and left in place while the device was in use. Removing the needle allowed the skin and subcutaneous tissue to close over the Portacath and protecting it from external infection. When the device was used intermittently, the skin and tissue had a chance to heal. However, some children required frequent or continuous use of their Portacath. The skin and tissue were damaged by repeated punctures. Rather than form a protective barrier against infection, the area overlying the Portacath could degrade, allowing infection to enter the device.(M10, M11, M13)

“Once the skin’s damaged in the portacath the infection risk is huge. The idea is that it’s random access, isn’t it, so. Not random, irregular, infrequent, enough time for skin to heal.” (M10)

One boy had his Portacath used continually for a period for several months and developed an infection in the skin around the device. There was no opportunity for the skin to heal and the infection spread into the soft tissues. Eventually, the skin and soft tissues broke down and the Portacath simply fell out of his chest wall.(M11)

“He had to have access at the time, so we couldn’t leave it uncovered, and the skin just broke down in the end, and that’s when the Portacath fell out.” (M11)

Participants reported that some children could have the same device in place for several years, for example if they were receiving treatment for leukaemia. Over time, however, the structure of the device could weaken and crack. This was a concern for children with central lines as the device was a direct conduit to the major blood vessel leading to the heart. Not only would a breach in the line bleed, but any infection could readily enter the blood stream and travel around the body. Damaged lines were repaired where possible so that the child did not have to have an operation for it to be replaced. The

repair was not as strong as the original line, and the line could break at the site of the repair.(M12) Breaches in central lines were viewed as emergency situations by professionals, which meant that children had to rush to hospital to ensure their safety.(M8, M19)

“Because it is a central line and it is an open system now... so we had an ambulance arrive to bring him to A and E to get it sorted.” (M8)

5.1.2 Treatment associated with the underlying condition increases the risk of infection

The treatment that children received for their underlying condition could leave children susceptible to infection. As a result of their medical needs, children spent a lot of their time in hospitals and clinics. Families and professionals were concerned that time spent in healthcare settings would expose them to further infections from other patients who were unwell.(M13, M14, M19)

“Everyone agrees he shouldn’t be in hospital because it’s a dangerous place for him to catch infections.” (M19)

Devices could become contaminated more easily as a consequence of the treatment that a child received. One young girl with cancer had previously been fully toilet-trained. The combination of both treatment and disease had left her temporarily unable to walk, and therefore unable to get to the bathroom in time. She was back in nappies, and her parents found it difficult to keep the ends of her central line from falling into her dirty nappy. Chemotherapy made her feel nauseated and she was often sick onto the line, increasing the risk of infection.(F7)

“And she was in nappies at the time, because she’d lost the use of her legs, so she...she couldn’t walk. So there was a worry about falling down, dirty nappy.” (F7)

Another girl had to have a colostomy fashioned and was covered with a bag which designed to seal close to the skin to catch the faecal matter which was excreted through it. This was placed very close to the site of her gastrostomy, and made it very difficult to

attach the colostomy bag securely. The faecal contents could leak onto the gastrostomy site, with potential to cause infection.(M17)

Barriers which protected the device, such as skin or dressings, were also affected by the disease or treatment.(P3) Some children with brain injury touched their device repeatedly, or picked at dressings to try and remove them.(P3, P19) Treatment with chemotherapy meant that the lining of the gut broke down and bacteria moved from the gut and into the bloodstream.(263) Some central lines were infected by bacteria which were able to cross into the bloodstream as a direct result of the treatment that the child had received.

“we caused the child, through chemotherapy or radiotherapy, to become really unwell” (P14)

Chemotherapy which was intended to cure the child of a life-threatening cancer could itself endanger the child’s life by putting them at risk of a CLABSI.

Children with cancer were also at risk of infection because their immune systems were damaged by the disease and by the treatment they received. Immune suppression was also a feature of some children’s underlying condition. These children were at increased risk of infection and could become seriously unwell from relatively minor infections which developed unchecked by their natural immunity.(M1, M2, F5, M6, F7, M8, M9, M10, M12) Families were therefore aware that the treatments which were intended to treat their child for their underlying condition could leave them at risk of significant infection.

5.2 The impact of device-related infections on children and families

5.2.1 Device-site infections

During my literature search, it appeared that device-site infections were rarely considered as significant complications by healthcare professionals.(84,85,88,89) However, interviews with parents suggested that device-site infections had a significant impact on the child and the family. Infections of the skin area surrounding a gastrostomy were common. Although less severe than bloodstream infections, they

nonetheless had a big impact on children's quality of life: infected gastrostomy sites could bleed and ooze fluid. Dressings needed changing frequently because of the discharge from the infected site.(M6) Discharge from the site soaked through onto clothes; pulling the clothes off was painful for the child and made the infected site more inflamed.(M9) Families spent a lot of time applying creams and dressings to try and control the infection.(M17, M18)

Device-site infections were painful for children. The location of the device meant that children could not participate in everyday activities without experiencing pain: gastrostomies were placed on the front of the stomach; Portacaths and central lines were usually placed on the front or sides of the chest, which could be touched easily. Sometimes, the skin could become so tender that even wearing clothes was painful for the child.(F4, M9, M16, M17)

"If you just put his t shirt on he would say 'it's rubbing on it and it's really hurting.'"(F4)

Using an infected gastrostomy to give medication or feeds was also painful for children. The gastrostomy was a "lifeline" through which the child received vital nutrition or essential medications which stopped them having seizures or which gave relief from painful spasms. Parents felt that they had little choice but to use the gastrostomy, thus inflicting pain on their child.(M9, M14) This example demonstrates how parents between two opposing views of the "good" parent – simultaneously wishing to protect their child from pain whilst at the same time trying to carry out tasks which were important for their health.(264)

Persistent gastrostomy site infections had a significant impact on the quality of life of one child with cerebral palsy. The infection was confined to the skin around the gastrostomy and thus was not considered to be a serious infection; however, the effect on the child was considerable. The pain that resulted from the infection meant that he was unable to tolerate any pressure on his abdomen. He was unable to sleep comfortably and was restless for much of the night. He could no longer take part in some aspects of physiotherapy because of the pain of lying on his front; nor was he able to use a standing frame comfortably. Antibiotics given to treat the infection interacted

with his other medications, thus his medical therapy was also affected. The infection eventually resolved after several years, and the improvement in his quality of life was considerable.(M16)

“He would literally just be pulling his knees into his tummy... but yeah, pull his knees in, it was horrible, and obviously that affects your sleep, and then you’re trying to do things, but when the button’s already sore.”(M16)

Portacath site infections resulted in additional complications. The Portacath was usually protected by a layer of skin and tissue. Infections around the site could cause the skin to break down, exposing the Portacath to the outside world. Organisms could enter the bloodstream through the exposed site, leading to potentially severe infections. In addition, the tissue layer which held the Portacath in place could be damaged by the site infection, and the Portacath could fall out.(M10, M11)

“It damaged the skin over it, and then after that the skin never recovered, and it, one day I was getting him in the car, my thumb just went over the top of the port, and the whole of the skin just sheared off, literally hanging there... I opened his coat and there’s blood, looked like he’d been shot, blood everywhere! That was a quick ambulance ride! And had it taken out, yeah. But that was, yeah, that was a simple skin infection that was.” (M11)

5.2.2 Central line associated bloodstream infections (CLABSI)

Bloodstream infections were frightening and traumatic events for families. The severity of the illness was often beyond anything that families had experienced before, leaving families with traumatic recollections of the events. Parents sometimes believed that their child would die as a result of these infections.(M2, M10, M11, M12, P8) The founder of a parent support group had witnessed her daughter’s central line-infection. Many years later, the memories of the event were still vivid and very distressing for her.(P8)

“I put her in the bed and they [nurses] came around and she started vomiting and thrashing about on the bed and her eyes were rolling back in her head... I

was sitting on top of her shouting – stay with us [PERSON 1], stay with us. I will never forget it.” (P8)

Another girl was so unwell that the clotting of her blood was affected: blood seeped from wounds including her gastrostomy, and she vomited blood.(M12)

“Within two hours had gone from being, not, not right, but unwell to being, you know, 40° temperature with blood pouring out of her PEG [gastrostomy] and, you know, and everything, it happened so quickly.” (M12)

There was little warning for parents or healthcare professionals that children might deteriorate so quickly. Children could be admitted to high dependency wards or ICUs for treatment of the CLABSI. These admissions were made more traumatic for parents as there was usually no space for parents to sleep by the child’s bed and they were separated from their child at the time that they were most unwell.(P12) Hospital admissions disrupted normal family life both within and outside the hospital walls.(162)

Other infections were less dramatic. Children were feverish and miserable, but did not require intensive care or resuscitation. Nonetheless, children were unwell as a result of a CLABSI and the infection needed to be treated.(F7,P3) Participants consistently emphasised the importance of treating infections as soon as there were any concerns around the central line.(P2) If a child with a central line developed a fever, they were assumed to have a CLABSI, and were expected to go to hospital immediately for further assessment. This often resulted in a hospital admission of several days and treatment with intravenous antibiotics.(F7, M10, M11, M12, M13, P3, P16)

*“Every temperature you’re going to hospital, because you have to, just in case”
(M11)*

Not all infections were successfully treated with antibiotics. Infections which could not be treated effectively with antibiotics could result in the removal of the central line.

“If it gets infected you might have to have the line out and a new one put in on the other side of your body.” (M2)

The threat of central line removal was an additional source of concern for families. Children required the central line because of their health condition, and without it their health could deteriorate further. Removing the central line was a significant procedure and meant that the child would have surgery under general anaesthetic.(M2, P17) If a new central line was inserted, then this involved further surgery and another stay in hospital.(M2, P3) Removing an infected central line had long-term implications for the care of the child.(M11, M12, P2, P3, P17) Some children were dependent on a central line for their survival. Replacing the central line became more technically challenging each time, and there were limits to how many central lines could be inserted during a child's lifetime. Central line removal helped resolve the infection, but could restrict the child's use of central lines in the future.

"There's only a certain amount of times you can have a line, I think it's only eight... And I know a couple of parents who've now run out, they've got stents in and everything, and their kids are very very young, because doctors don't look ahead to the future necessarily, they go well this child needs access, whack one in, you know, or whack a temporary line in, you know, and you're going oh no, that's a whole, you know, a site we've lost." (M11)

There was sometimes a delay between removing an infected central line and the insertion of a new one.(F4) Without the central line, children needed to have peripheral cannulae inserted to receive antibiotics and other treatment. Cannulation was painful and distressing for children, especially when there were repeated attempts.(C11, C12, M18)

"I just needed a new one [central line]. And I went through about a cannula a day, because I had no veins." (C12)

Other families felt that peripheral cannulae would be preferable compared to the risk of further infection. One girl had a central line inserted to receive chemotherapy; her parents had discussed the possibility of central line-infection and decided that they would prefer to have the line removed completely if it became infected. The girl would only need chemotherapy for another few months, and thereafter would only need to

have occasional cannulation. For this family, the risk of central line-infection outweighed the benefits of having the device replaced.(F1)

“I think we do have to make a decision if they [central line] do get infected about having them taken out.” (M1)

Children who had recurrent infections in a central line could have the device changed to a Portacath to try and minimise the number of device-related infections.(F7, P14) This was a difficult decision for the families as it meant that their young child had to undergo another significant operation under general anaesthetic. One father explained that his daughter had had numerous suspected CLABSI. After a year of recurrent admissions to hospital for treatment with antibiotics, the family made the decision to change the central line to a Portacath, in the hope that the Portacath would be less liable to infection.(F7)

“I remember thinking at the time when we took her to, to be put to sleep for the operation, you know, am I doing the right thing.” (F7)

Although the father was concerned about the risks of putting his daughter through a general anaesthetic and further surgery, these concerns were outweighed by the potential benefits of the Portacath compared to the central line. The risk of central line-infection and the potential consequences influenced families’ treatment decisions. These examples demonstrate how the phenomenon of central-line infections was experienced differently by families, influencing their decisions around device care.(249)

5.2.3 Disruption to normal life associated with hospitalisations for infections

Device-site infections were usually managed at home. However, the treatment for central line-infections (whether proved or suspected) required admission to hospital and treatment with intravenous antibiotics. These hospital admissions were disruptive for children and families. Children could become unwell rapidly and at any time of day or night. Families had to plan their lives to ensure that they could attend hospital rapidly if their child became unwell.(P20) Children already spent much of their time in hospital as a result of the underlying health condition, thus treatment for a device-related infection resulted in an additional disruption to family life.(M2) Hospital admissions prevented

children and families from carrying out their normal routines: they could not attend school or clubs and activities.(P12,P16) Special events, such as parties or holidays were also affected.

“I always say to families, always have a backup plan so if you planned a birthday party and what you are going to do, what happens if they get a temperature always plan something as a backup so that you don’t get too disappointed if it doesn’t happen.” (P20)

Some children had numerous hospital admissions for suspected CLABSI, which stopped them attending school regularly.(F7, M10, M20) Infections could prevent a child’s return to school even if the underlying medical condition was no longer a barrier. One child was considered well enough to go back to school but developed repeated central line-infections which needed treatment in hospital. The repeated admissions for infection delayed her return to school.(F7)

“We tried to get her back sooner, but she, she kept ending up back and forth from hospital with a lot of infections.” (F7)

Hospital admissions were disruptive for parents and the wider family. Families were advised to take their child to hospital as soon as they developed a fever. As a result, parents had to leave work at short notice to take their child to hospital for admission. It was difficult for parents to explain to their superiors at work and this led to additional tensions for families.(F7)

“I would get a call and say, you know, [Person 1]’s ill, come home, we need, we need to take her to the hospital and then I’d have to drop everything, that would be me disappeared from work for two or three days, minimum... So I got quite a few meetings with managers, quite a few disciplinary letters and stuff like that.” (F7)

Taking time off work to accompany their child to hospital during an infection also had financial implications which impacted on the family as a whole.

“When she goes into hospital I take unpaid leave, so the financial side...” (M12)

Families made significant changes in their lives to ensure that their child could access hospital care if they had an infection. One father explained that he had avoided taking his daughter on holiday when she had a central line in place. He was concerned that she would be unable to get urgent medical attention if she became unwell while they were abroad. Any trips or visits away from the local area were carefully planned to make that there was a hospital nearby.(F7)

"I wouldn't have dared to leave the country... I would have wanted to be within 10 miles of the nearest hospital." (F7)

Another family had limited access to transport, and had therefore moved house to be closer to the hospital so that their daughter could get medical attention if she developed signs of a central line-infection. Moving house had meant that the child could no longer attend her old school, and there were no spaces available in the schools near her home, undermining her access to education.(F5)

Attempts to minimise the consequences of device-related infection had a significant impact on the everyday lives of families and limited their ability to lead a normal life.(244)

5.2.4 Fear of infection

The fear of infection was always present for some families, adding to the emotional burden experienced.

"I always worry. I will always worry until that thing is out." (M2)

Families were aware of the consequences of CLABSIs from their knowledge of the experiences of other families.(M1) Families could see when a child became unwell on the ward, and parents shared information and stories between themselves.(M11, P8)

"I know a couple of kids who've died [few words 54:33], so it's always there, you know, to the point where even when he's asleep and he doesn't wake up when I think he should wake up, I have to go and just check he's still breathing... And whenever you feel settled with it, you know, you'll hear of another child who got an infection, didn't make it." (M11)

The unpredictable progression of the infection added to the fear that parents experienced.(M12) Parents already feared that their child might die because of their underlying medical condition, or because of consequences of treatment. The fear that their child could die from a device-related infection was *in addition* to the fear that families already experienced. (F7, M10, M11, M12, P8) A father described how every time his daughter had regularly developed a fever after her central line was used to give medication. Every fever resulted in an urgent trip to hospital, and treatment with intravenous antibiotics. Each time, he felt fearful that this was a significant central line-infection from which she would not recover.(F7)

“It [suspected infection] never got easier to deal with, because there was always that worry that, you know, maybe this time she’ll go in and it will be something really serious and she might not come out.” (F7)

5.2.5 Loss of control associated with infection

In addition to the fear of serious illness, families felt frustrated when a child developed a device-related infection. The disruption that families experienced as a result of device-related infection contributed to this feeling. Device-related infections could occur without warning, and this unpredictability added to the loss of control that families experienced.(P20) Families were aware that infections could be severe and some felt that they had little choice but to rush their child to hospital as soon as infection was suspected.

“It’s not a decision we make, it’s made for us” (F7)

Parents felt helpless when their child developed a serious device-related infection. A mother described her frustration when her child developed a severe septicaemia as a result of a central line-infection. As a nurse herself, she knew that there the clinical team were working efficiently to treat the infection, but as a parent, she felt that she should have been able to do more.(M12)

“They were doing what they needed to do, but as a parent it’s horrible, it’s, you know, to kind of, because you can’t control, and you’re not in control, and I think that is what it comes down to, that you’re not in control of what’s, what’s

happening, who's doing what, and nothing happens quick enough! You're just like do something." (M12)

The uncertainty associated with device-related infections exacerbated the feeling that events were beyond the control of families and professionals.(P16) Children could become unwell at any point, therefore many families kept an overnight bag ready, prepared for a hospital admission of several days.(P6) Once in hospital, test results to confirm the presence of infection in the device often took several days to come back, and families were left waiting during this time.(P14) Sometimes, children felt well and the infection was detected on routine monitoring by healthcare professionals.(P14) Even when the tests were clear, the suspicion that the device was infected remained.(F7)

"She kept ending up back and forth from hospital with a lot of infections, some of which I think were down to the [central] line to be honest because we never really got an answer as to what it was." (F7)

Families spent more time waiting for surgery for the device to be removed or replaced, which added to the sense of frustration they felt.(P6)

5.2.6 Guilt/responsibility for apparent failures of infection prevention and control

As I describe in chapter 3, families took on the vast majority of everyday device care. Families felt that they were responsible for ensuring that the device was kept clean and was used safely.(M2, M11) As a result, when a child acquired a device-related infection, some families felt that they were to blame for not having provided adequate care.(F4, M12) One mother undertook all the central line care for her daughter, including administering medications and feeds, and taking blood samples. When her daughter developed a central line-infection, the mother explained that she had felt personally responsible. She deliberated over the events leading up to the infection, trying to identify any mistakes that she had made in the care of the device.(M12)

"You do, you blame yourself, and you know, you just think did I do this?" (M12)

For this mother, the responsibility that she felt for carrying out appropriate device care was an extension of the responsibility that she felt as a parent. She felt that the guilt that

she had experienced after her daughter's infection was similar to the guilt that she felt about other negative parenting experiences.(M12)

"I think you blame yourself as a parent for anything, you know, it doesn't matter whether it's a line-infection or they're just (...) I think that's just the joys of being a parent I think." (M12)

Parents anticipated the feeling of guilt that they would experience if their child developed an infection. One mother explained that although her son had never had a central line-infection, she was always frightened of providing device care. The mother felt that she would be responsible for any infection that did occur.(M2)

"You are the one responsible for him catching an infection because you have not done it properly and then you have to go back into hospital and have it all sorted." (M2)

Another mother explained that she was not always completely stringent with aspects of her son's gastrostomy care as she felt the risk of infection was low and potential consequences were negligible. However, her approach was different to central line care. The severe consequences that could result from a central line-infection meant that she was rigorous about carrying out these aspects of his care.(M11)

"I could never live with myself if he got an infection, it was after I had done all the dressing change." (M11)

The anticipatory guilt that the mother expected to feel if her son developed an infection affected the care of the device.

One mother had concerns about the quality of care that her son had received from care assistants and nurses in their home. She did not feel confident that the professionals would protect her son from infection. By undertaking all his device care herself, she felt that the care would be carried out correctly and her son would be protected.(M19)

"Whereas if someone else does them and then he gets an infection, you're like well did they do it wrong?" (M19)

The mother actively sought to shoulder an increased physical and emotional burden in order to provide her son with the best care she could envisage. These examples demonstrate the emotional burden that families undertook in the care of the device. Families carried out device care in the knowledge that they would feel to blame if there was an infection. Accepting responsibility for device care also meant that families had to accept responsibility for infection.(139,265)

5.3 Work that families undertake to keep the device free from infection in everyday life

Although all participants interviewed were conscious of the need to minimise the risks of infection, they also described the challenges, tensions and trade-offs that routinely had to be made. Families reported extensively on how competing priorities interfered with using the device in an aseptic manner. Balancing the competing demands of the device against the other demands of family life was complex for families. Families were engaged in a continual process of trade-offs which required considerable expertise to negotiate. This expertise was not taught: rather it was a gradual process where families established their own priorities with regards to device care, drawn largely from their own experiences and those of other families.

In addition to the technical work of using the device outlined in section 3.3, the device had to be maintained in good condition and kept clean in order to reduce the risk of infection. In *Table 5.3.*, I outline the IPC practices associated with each device, as described to me by the families.

Table 5.3. IPC tasks carried out by families

Device	IPC tasks
Gastrostomy	<p>Change the gastrostomy “button” every few months</p> <p>Rotate the gastrostomy tube daily (especially when newly formed)</p> <p>Clean around the gastrostomy insertion site at least daily</p> <p>Inspect for any signs of infection such as skin reddening or discharge</p> <p>Apply creams or dressings if infection is suspected</p>
Tracheostomy	<p>Change the tracheostomy tube every week</p> <p>Changes the tapes securing the tracheostomy tube every week</p> <p>Clean around the tracheostomy site as needed</p> <p>Apply creams or dressings if infection is suspected</p> <p>Inspect for pressure sores, skin reddening or discharge</p>
Central-line	<p>Change the waterproof dressing over the insertion site at least weekly – more often if soiled or peeling</p> <p>Inspect the dressing at least daily to ensure clean and secure</p> <p>Be vigilant for any change in skin colour or tenderness around the device site</p> <p>Ensure clamps are secured and the line is not kinked or cracked</p> <p>Ensure line is kept dry at all times, including during bathing</p> <p>Ensure that the lines are kept securely in a “wiggly bag” to minimise the risk of contamination</p> <p>Seek urgent/emergency medical advice if any fever or suspicion of infection</p>
Portacath	<p>Be vigilant for any change in skin colour or tenderness around the device site</p>

IPC practices formed part of the everyday life for children with invasive devices. However, carrying out these practices required families to make significant adjustments to their daily lives in order to reduce the risk of device-related infection. As a result, activities which had previously seemed routine became full of difficulties for families.

“A never-ending battle to us just to keep it [central line] clean.” (F7)

Families had to make sure that the care of the device was carried out, in addition to the child’s other needs and the needs of the rest of the family.(M6) Device care had to be worked in to the other routines of the family, and became part of the family’s everyday life.(M12)

“And at some point among that we fit in dinner and homework and all the normal kind of things, and school discos and all that sort of stuff.” (M12)

Care of the device was not evenly distributed between the care-givers in the family. Three families (M10, M13, M19) lived as single-parent households: the mothers in these families were responsible for all the device care that was not undertaken by professionals. One child (F7) lived primarily with her father who kept the device clean. The other sixteen families had two parents living in the family home. Although both parents lived in the home, one parent (usually the mother) became the primary carer for the device. Mothers had spent more time with their children in hospital during the period of device insertion, thus they were more familiar with the device at the beginning than many fathers. Once the child went home, mothers were more confident with the care of the device, and continued this role.

“As much as [child’s father] would try and do it very carefully, because I have been in the hospital for the six weeks so I was the one that was used to watching them [nurses] doing it.” (M2)

Children with Portacaths had a different experience. For them and their families, the device was protected underneath the skin, and therefore required minimal care. The child’s own body kept the device safe from infection on a daily basis.(F4, F5, F7, M13)

“We take out the needle, it’s all off closed.” (F5)

5.3.1 The basics of good infection control

Families felt that general hygiene precautions, such as keeping the home clean and washing hands, were essential to keep the device free from infection.(M2, F5, F7, M10, M11)

“We take more care about cleaning.” (F5)

In practice, this was difficult to achieve. The realities of living in a busy family home with other children and pets meant that regular cleaning could not keep the home pristine. Families had to be realistic about what they could maintain without spending all their time cleaning.(M11) This example demonstrates how ensuring a spotless home environment to hospital treatment-room standard conflicts with everyday family life.

“So, you know, anyone could have walked anything through the house, and even though try and Hoover every day and mop every day, that’s like good then for two minutes of the day, and then that’s it! It’s like you can’t be precious about it, certainly not in our house, because you just, you’d drive yourself insane, you’d be absolutely insane, trying to keep on top of it.” (M11)

Good hand hygiene, by means of thorough washing and the use of alcohol hand rubs was seen as important by families.(M2, M19) Despite recognising the importance of clean hands, complying with this requirement was not always easy. During a field visit, one mother showed me her hands: the skin had broken down through frequent washing and breaches in the skin meant that using alcohol-based hand gel was very painful. As the main carer for her daughter, she had to continually ensure that her hands were clean. There was no time for the skin to heal and recover, and using gloves became painful because of the contact with her skin. Continuing to comply with guidance on hand hygiene meant undergoing pain.(M3) One child with a central line became very concerned with avoiding infection, and would continually wash his hands to make sure they were clean. As a result, his hands were sore and painful.(M8)

“He has always got sore hands because he is always washing his hands.” (M8)

Bathing was a particular challenge for children with central lines. Families were told by professionals that the external ends of the lines had to remain dry at all times; they also had to make sure that the dressing covering the entry into the skin was water-tight.(C1, C12, M1, F1, M2, F7, M8) Each bath time required significant preparation from children and families to ensure this. Families used combinations of additional dressings, plastic bags, tape and swimming vests to try to keep the line dry. These processes took a considerable amount of time and effort from parents.

“The whole issue around washing and bathing, washing and bathing is definitely the biggest deal.” (P8)

Children could also become afraid that the device could become infected. One boy was very concerned that the dressing over his central line would unseal, leaving the line open to infection. He became repeatedly inspected the line site to ensure that the dressing was tightly sealed. The fear pervaded every aspect of his life, including every day activities like bathing.(M8)

“He is scared of having a shower because the water is going to run down him and he thinks it will go onto his line and seep into the dressing. So every time he goes in the bath he inspects all the way around the dressing to make sure there is no way that the water can get in.” (M8)

These examples demonstrate that even simple IPC measures such as washing hands or bathing could have a significant impact on the everyday life of the child and family.

5.3.2 Keeping the device in good condition

Ensuring that the device was kept in good repair helped reduce the risk of device-related infection. Parents were expected to inspect the device thoroughly to make sure that there were no breaks or cracks in the device, and some components were replaced regularly. Central line catheters were clamped when not in use to prevent blood from refluxing back into the line where it could stagnate. Stagnant blood could block the line, and was a possible focus for infection. It was, however, quite easy for the clamps to loosen, and families were supposed to monitor their position regularly to ensure that they were still in place.(M2)

“There had occasions when people suddenly realised the clamp has been undone and they don’t know how long for” (M2)

Some devices were replaced on a regular basis to ensure that they remained safe to use. Gastrostomy tubes or “buttons” were replaced every 3 – 4 months. (The button sits on the surface of the skin, and is the point where the stoma from the stomach is brought out onto the skin.) Replacing the button was an attempt to minimise the risk of infection which was harboured in the device itself. Although the replacement was sometimes done by nurses, it could also be carried out by parents. Changing gastrostomy “buttons” was a source of pain and distress to children: some needed pain relief or even sedation to tolerate it.(M9, M14)

“We had to do that under sedation, because it was very sore, and she’s very, while she copes day-to-day with the tube really well, she’s terrified of button changes.” (M14)

5.3.3 Cleaning and dressing the device site

The site where the device entered the body was a potential source of infection, and the skin needed to be cleaned regularly. Gastrostomy sites required daily cleaning with wipes or in the bath: this was carried out by families.(C9, M11, M15, M16, M17, M20) Gastrostomy sites sometimes required cleaning more often, for example if there was discharge from the site. Parents felt that regular cleaning was important to reduce the risk of skin infections.(M20) Some children had support to clean the device site in school, ensuring that the site was cleaned more thoroughly than the child could manage alone.

“No, I prefer them [support workers] doing it, cause if I do it, it seems a bit, it’s a bit hard from a certain angle.” (C20)

The skin around the tracheostomy site was cleaned daily by families, and a soft dressing applied.(M3) Dressings around a tracheostomy were also changed daily by families, and the skin cleaned with sterile water or wipes before each dressing change. Soft tapes were passed around the child’s neck to secure the tracheostomy: families were advised

that these should also be changed on a daily basis (M6), although this was more challenging to carry out.(M3, M19) Neck tapes could cause pressure sores, leading to skin breakdown and subsequent infection.(M19)

Central line sites were cleaned with antiseptic solutions before being covered in a protective dressing which was designed to be adhesive and provide a water-tight seal. Although effective at protecting the breach in the skin, this meant that the dressings were difficult to remove and could be quite painful.(M2, F7, M19, P1, P20) The skin beneath the dressing could remain covered for several years with only brief intervals when it was cleaned. It could easily be damaged by the repeated removal of adhesive dressings.(M8, P1)

"[dressings] would almost be cemented to her skin, and getting them off was an absolute nightmare." (F7)

"There is a whole patch around the line that is permanently dressed and it is red raw." (M8)

Some dressings were impregnated with an antimicrobial solution, and designed to reduce the risk of infection in a newly inserted central line. Unfortunately, these dressings were highly adhesive: removing them was a painful experience, especially during the first few weeks when the wound was still fresh.(M2)

"When he had it first done they had a little donut thing...that was horrendous. It was really sticky and it was stuck not only on him but the line was stuck on him and the stitches were stuck on him and obviously trying to get all of that off without it being too painful was absolutely horrendous." (M2)

Removing the dressing was not without difficulties: the line could be pulled or damaged in the process.

"We have had a mum accidentally cut the [central] line with the scissors that she was using to get the sticky dressing off." (P1)

Dressings were changed weekly, or when the dressing no longer protected the wound adequately (e.g. if the dressing became wet, dirty, or if the edges of the dressing peeled away from the skin). The dressing was inspected every day by children and families to ensure that it was still intact.(M8, M11) Often, nurses would make a planned visit to the child at home or at school to provide central line care. Families were expected to carry out these procedures if additional cleaning or dressing was required between these visits.(P10, P17, P19, P20) Parents had to make the decision to take on this role for their child, or risk leaving them open to infection.(M2, M19, P1)

“Sometimes it [the dressing] would unpeel and I think well I can't wait three or four days for someone to come. I can't phone them [nurses] to just come and do it. I will have a go at doing it myself.” (M2)

Changing the dressing over a central line was not a simple procedure. Great care was taken by families and professionals involved to make sure that no infection could enter the site during the process. This was particularly challenging when children could not assist in the process, or if the insertion site was in a difficult place. One child had a central line inserted in just below his armpit. He had other medical needs and was unable to move his arm independently. This made it especially difficult for the insertion site to be kept clean and free from any contact with the rest of his body when the dressing was changed. The situation was made more difficult because he had sustained a fracture of his shoulder, which limited his movement even further.(M19)

“We had to change the dressing every day, and obviously it was a sterile procedure, so doubling, double gloves, and then sterile gloves on top of that. And it was, oh, just, every time we did it was just really convoluted, wasn't it [C19]?” (M19)

Cleaning the device was an additional burden for the families at a time when they were already overloaded with concerns about their child's health and the medical treatment that they were receiving.

“Changing the dressings, having to keep everything sterile, that took some getting used to... that’s on top of all the treatment that she’s undergoing as well so it was a lot to take in.” (F7)

Additional infection control measures added to the burden experienced by families. Cleaning the skin could be very painful for children, particularly if antiseptic wipes containing alcohol or chlorhexidine solution were used.(C12, M19) Cleaning the skin started soon after the device was inserted: the physical wounds were new and scars were raw. The skin around the insertion site was very sensitive and cleaning was painful; removing the existing dressing meant that scabs newly formed over the wound were ripped off and stitches were pulled.(M2)

“At the beginning it was raw and sore. It is an open wound.” (M2)

Some children had vivid memories of their early experiences of skin care:

“But about an hour after I woke up they needed to put a new clean dressing on, so, with the alcohol wipes, which really really hurt, I can just remember crying because it hurt so much.” (C12)

Other children had a less traumatic experience. One child had had several other invasive devices (including a central line) in the past: in comparison, the gastrostomy was seen as relatively low-maintenance and required little additional care.(M11) Cleaning a gastrostomy site was no different to regular bathing or washing. The gastrostomy was seen as part of the child, and was treated in the same way.(M11, M15, M16, M17, M18)

“We just wash it like you’d wash any other part of your body.” (M16)

However, gastrostomy care could be challenging. Removing the adhesive from a gastrostomy dressing also required significant cleaning which could damage the skin, causing pain to the child and leaving the skin open to infection.(M9) Cleaning the gastrostomy became more complicated if a child had more than one care need, for example a gastrostomy and a colostomy. Cross-contamination could occur between faecal matter that leaked from a colostomy when the bag was being changed and the

healing wound of the gastrostomy. This added to the complexity of providing care to the child.(M17)

“Any time I touch the stoma it’s always with gloves...the Mic-Key[gastrostomy] buttons, because we don’t, it’s not awful, I do it with washed hands. But if we are going from one to the next we just either take off gloves and wash hands, or change gloves.” (M17)

Thus the process of cleaning the device site and protecting it from infection could be a difficult and onerous one for families.

5.3.4 Equipment to carry out device care

The equipment used with the device had to be clean or sterile to minimise the risk of infection. A child with an invasive device required a great deal of additional equipment which families had to store in their homes. Syringes were used to give medications and fluids via the gastrostomy. Gastrostomy feeds were delivered by long catheters (“giving sets”) which were either attached directly to a bottle, or given at a prescribed rate by an electronic pump. Some families used gloves when carrying out care, while others used antibacterial hand gel. Children with gastrostomies often required medications which were drawn up into syringes before use. The syringes were often reused, and families had to ensure that the syringes were cleaned each time. Ensuring that equipment was clean enough to use was time-consuming for families.(M6, M14, M15, M16, M18) One mother described how she had been using a steriliser to clean through medication syringes, until advised not to by a dietician. The recommendation instead was that the syringes were washed through with cool boiled water, and then kept in the fridge in clean plastic tubs. This was much more time consuming than using a steriliser, especially as this was a daily activity.(M6)

“But actually the routine you had to go through, of putting them in the fridge and rinsing them out with cool boiled water, all that stuff. Why can’t I just rinse it out with normal water and shove it into the steriliser, it’s so much easier?” (M6)

As syringes were used, cleaned, and re-used, the plastic began to degrade. Over time, the inside of the syringe became sticky with medicine residue even with thorough cleaning.(M14, M16) Families learned which medications always left a residue and that syringes used for these medications could not be reused. Syringes were carefully inspected before use and families decided if they were safe to use or not. Families had to judge when syringes were safe to continue using, or if they needed to be replaced with new equipment.

"I kind of know how long I've been using them, I check them." (M16)

The decision to request new supplies could be influenced by the perceived availability of resources in the NHS. One family had recently moved to England and had previously had to pay for all their child's equipment themselves: the mother felt they were more inclined to re-use equipment as a result of this experience.(M14)

"I guess because we were paying for them as well, we would use syringes probably for two weeks at a time." (M14)

Children with central lines had to have a supply of cleaning wipes, syringes, gloves, dressings and blood bottles kept in the home. Using a Portacath required the use of numbing spray or cream, disinfectant cleaning preparation, and needles in addition to the equipment required for central line use.(F4, C5, F7, M10, M13, M14) Even if the technical component of device care was carried out by healthcare professionals, families still had to have the equipment available. Much of this equipment was disposable or replaced on a regular basis thus families needed a considerable supply to be kept in the home.(M6)

Supplies of equipment were only available from specialist suppliers, and were delivered on a monthly basis. Some families received a vast range of dressings and cleaning solutions to try and minimise the risk of infection, which took up valuable storage space.(M17) Family homes were sometimes overrun with supplies, leaving little room for personal possessions.(M3, M8, M12) The supplies were too numerous to be hidden away or concealed, and their presence provided an additional reminder of the child's illness and their medical needs.(F4) Families were unable to separate the child's device from their normal home life.(245,251)

“It is only now in the last week where he has stopped having bloods done every week that we have kind of feel like it is our bedroom.” (M8)

In addition to storing equipment at home, families had to carry equipment with them wherever they went. Caring for a child with a tracheostomy meant carrying a significant amount of equipment at all times in case the tube blocked and the child stopped breathing. The kit included: spare tubes in case the tracheostomy became blocked and needed replacing in an emergency; a battery-powered suction machine and catheters to remove any secretions blocking the tube; dressings; scissors; a bottle of sterile water; and hand gel.(M3, M6) This equipment filled a large rucksack or a shopping trolley and was heavy and cumbersome to carry around. If a child had two devices, then families had to carry twice as much equipment.(M6)

“We need to take with us a suction machine...pads, obviously nappies...emergency box, which has the spare trachy, trachy [few words 9:27] and all that sort of stuff in it, got to take out something to hold it, because the gastrostomy comes out, [few words 9:32] gastrostomy emergency kit... I need the food, spare food, and what else is in the bag? Oh, spare clothes obviously. So I have all that, and oxygen. So when we go, go anywhere, we’ve got like six or seven pieces of equipment to take.” (M6)

Families were also responsible for ensuring that children had equipment with them in case of any problems with the device. Children with gastrostomies and tracheostomies carried spare equipment with them in case their device came out accidentally or needed changing.(M10) This included replacement gastrostomy or tracheostomies tubes, cleaning solution, syringes, gauze swabs, and dressings. The equipment was provided in sterile boxes which were much larger than the actual equipment and added to the paraphernalia that the family had to carry with them. One solution was to remove the equipment from the cumbersome sterile packaging and place it in clean plastic tubs. This meant that it was more practical for families to carry with them, although the equipment was no longer sterile.(M3,M6,M14) One mother explained that she felt the risk of inserting a non-sterile gastrostomy tube was small compared with the benefits of carrying the equipment in a smaller box.(M3)

“This is her spare Mic-key [gastrostomy] button, if it ever comes out. Because the box it comes in, it’s massive and it’s got all these tubes that you don’t use. To get it compact in the bag, I’ve just put it in here [indicates plastic box] and...the – some of the people that look after her complain ‘cause, you know, it’s supposed to be sterile, but, well, it’s going in her stomach. You know, like, children eat mud, don’t they? So.... So, you know, if they’re not happy, then I – it’s just tough, as far as I’m concerned.” (M3)

In this way, families sought to normalise the demands of IPC practices by integrating these requirements into their everyday life.(162,168)

5.3.5 Balancing risks and restrictions in everyday life

Rather than stringent adherence to IPC practice, families made pragmatic decisions about device care. One example was the choice to wear gloves when clearing a tracheostomy. Children with tracheostomies often needed emergency care to clear their airway of mucus and saliva. Any delays in carrying out this care would lead to an obstruction in the child’s airway, causing distress and starving the child of oxygen. Under such circumstances, waiting to put gloves on was not seen as an option. (M3, M6)

“It’s an emergency [Person 5], stop trying to peel the catheter apart, do you know what I mean, just rip it, get it open...and you can’t be sterile like...you know, like there, with gloves on and all that sort of stuff.” (M6)

Ensuring that children were able to take part in normal childhood play required parents to be vigilant for potential infection risks. Some activities were restricted, while others required parents to carry out additional work to ensure that the child was safe.

Swimming was an area of particular concern for children with invasive devices. Children with gastrostomies were advised that they could swim, provided that the water was clean and the skin site was healthy.(M20) The situation was different for children with central lines. Families were usually advised that children with central lines could not swim as water could enter the line or the insertion site.(M1, F1, M2, C2, C7, F7,

M8, M11, M12, P2, P10, P20) Children were aware that the invasive device imposed restrictions on their lives.

“She wants to go swimming but she knows she can’t.” (M1)

Some children attempted to rationalise this by proposing that they were not interested in the activities that they couldn’t do, or that they preferred other activities.(C2, C12)

“I don’t like swimming anyway so it’s fine.” (C2)

Children who had gastrostomies were allowed to swim, but families were nonetheless aware of the associated infection risks. Again, they engaged in the work of managing trade-offs. Families made an assessment to see if it was safe for the child to go swimming: if they felt concerned that the gastrostomy looked infected then the child could not swim. Some families tried to reduce the risk of infection by placing restrictions on where and when their child could swim. For example, by only using pools with limited access to the public (e.g. at respite facilities or in private health clubs) and by only swimming at the beginning of the day when fewer people had been in the pool.(M8, M15, M20) Others felt that there were no restrictions to swimming, and that this was a normal activity for their child.(M8, M9, M16)

“He gets normal baths and he goes swimming, so kind of what’s the difference?” (M16)

Toys were also seen as potential sources of infection from which families had to protect their children. Concerns about infection restricted children’s access to play rooms when they were in hospital as parents were worried about allowing them to share toys with other children. Families felt that they had to bring their own toys with them which they could keep clean. Even when toys were labelled, they would still be used by other children or go missing. This placed additional responsibilities on the family to ensure that the toys that their child used were safe.(M6)

“We had stuff taken, you know, people come take stuff out your cot.” (M6)

Accessing public play areas meant additional work for the parents to keep the child safe by maintaining a clean environment. One mother took her child to a soft play centre

with his siblings although this meant that she spent the entire visit trying to keep his devices clean. While other mothers were able to socialise with each other, she spent her time wiping equipment clean.(M10) In this way, IPC practices impact on the social lives of children and their families.

“It’s about being able to completely sanitise everything for that point.” (M10)

Families made complex decisions based on their experiences of the child and their device to manage infection risks while continuing to take part in leisure activities.

Going on holiday with a child with an invasive device was a significant undertaking. Families were limited in where they could go on holiday. Children with central lines had to stay away from sea water, and were advised not to play with sand on the beach.(P6, P8, P20) This had an impact on relationships within the family circle as children with central lines could not take part in beach holidays with their extended families.

“We couldn’t go there [the seaside] anymore because we weren’t allowed to go on the beach.” (P8)

Interacting with others who did not understand their child’s requirements made travelling difficult for families, and led to breaches of IPC. Explaining the child’s needs to airport security staff was particularly problematic. One mother was carrying a sealed container of sterile water so that she could mix a gastrostomy feed on the flight. In order to take the container on the flight, she was asked to break the seal and drink some of the water, thus making it unsterile, and potentially introducing infection into the feed.(M3) Even when airline staff had some experience of travelling with children with invasive devices, it was difficult for families to explain the significance of infection control measures to them. One girl who was dependent on nutrition she received through a central line was asked to disconnect the bag of PN so that it could be placed in an overhead locker during the flight. The airline staff were familiar with children who had their gastrostomy feeds disconnected during the flights, and assumed that the same process could be used with a child with a central line. It took her mother some considerable effort to explain to the airline staff that disconnecting the nutrition from the central line was a significant procedure which required sterile equipment and

expertise to carry out, and that this was not suitable to carry out on a crowded aeroplane.(M12)

“We got on the aeroplane, and obviously she, we had a bag running so she was on a PN, and they were like you need to put her backpack on, up in he thing. Like we can’t, it’s attached and they’re like well you have to disconnect it, you can’t leave it on...” (M12)

5.3.6 The child’s medical condition influences the decisions that families make

The decisions that families made around IPC depended on the context of each particular decision, framed in the circumstances of the family’s life. The balance between minimising device-related infection and maintaining a normal family life depended on the individual background of each child and their family. This balance was influenced by the child’s medical condition. Children 1, 2, 5, 7, and 8, had a device inserted as part of their treatment for cancer. The expectation in these families was that the treatment would come to an end after a few years, and that the device would be removed. For these families, the device was a temporary measure to treat an illness that they expected would be cured. The disruption to the child’s normal life was seen as temporary. Maintaining the device was simply something that had to be done as part of treatment. Disruptions to the child’s normal life were also part of the treatment, and would resolve after the treatment stopped.

Other children, such as children 6, 11, 12, 14, 20a, and 20b, did not have such a clear disease pathway. Some children had a number of complex medical problems but no diagnosed condition (syndrome without a name – SWAN) and, as such, neither families nor professionals knew what the future held. Others had a diagnosed syndrome which was so rare that there was no definitive information available about outcomes or prognosis. These families could not wait for the treatment to stop or for the condition to improve before establishing a normal life. They had to build a life around the device in the long-term, but with the expectation that their child’s underlying condition could deteriorate at any moment. As a result, activities of normal life became more important. Two children with SWAN (child 11 and child 12) had experience of swimming with a central line in place against the advice of their clinical team. But the swimming was not

an act of careless defiance or ignorance on the part of families. Instead, it was part of the consistent theme of managing trade-offs that is a feature of my analysis. In order for the children to go swimming, parents spent a long time covering the line with dressings to make sure that it stayed as dry as possible. Parents felt that it was important for children to continue activities that they enjoyed although this meant spending a considerable amount of time and effort trying to protect the device.

For another child, the situation was less straightforward. His condition had been relatively stable until a severe illness had led to a prolonged hospital admission. His mother knew that his life-span was limited, and that a device-related infection was likely to be fatal. For this family, avoiding infection was quite literally a matter of life and death. His mother prioritised device care above the aspects of his life, such as attending school, in order to keep her son alive.(M19)

5.4 Technical conflicts in maintaining infection prevention and control practices

Families felt that they were expected to provide hospital level care, but without access to the resources that were available in hospital. Families were left to fill the gap in provision, either by committing more time to device care or by buying additional equipment themselves.

5.4.1 Families do not have access to adequate medical supplies to carry out device care

A lack of medical supplies made IPC more challenging for families in the community. Disposable equipment, such as gloves or syringes, was readily available for professionals in healthcare settings or when they visited the family home to provide device care. However, families were expected to provide device care without the same access to supplies as professional carers. Community nurses who came to the home used sterile water and medical gauze swabs to clean around gastrostomy sites; families were expected to clean the area with what they had in the home.(M20) Although reassured by professionals that they did not need medical equipment to provide care, families realised that this advice was inconsistent with the practice of professionals. Some families made the decision to follow the practice rather than the advice given by professionals, and sought out their own supplies to emulate the care provided by nurses.(M20)

“The community nurse will come out and show you how to clean it, and they’ve got lovely swabs. And they go oh, but kitchen roll is fine. And they’ve got, you know, the special water...So I buy swabs from Amazon.” (M20)

One mother explained that the community nurses and school assistants who cared for her son were all provided with gloves to use. However, gloves were not provided for parents, who were expected to undertake nursing tasks without access to the same equipment. She believed that the reason for restricting supplies was financial, and influenced by limited NHS resources.

“Yeah, we don’t use gloves, cost too much apparently.” (M9)

The supply of syringes used for drawing up feeds and medications could also be restricted which meant that families had to wash and re-use equipment. These tasks imposed an additional time burden on families which was not accounted for in the cost of device care.(M9, M14)

The lack of supplies was not confined to gastrostomy care. One boy with a tunnelled central line had the dressing over the entry site changed every day because of the amount of discharge from the site. His mother and carers were shown how to do this as an aseptic procedure, using sterile equipment. However, they were only able to access limited supplies to carry this out, which meant that they had to improvise. This was an additional source of worry for this mother, who was aware of how the care of the device should be delivered to her child and had taken on this responsibility, but did not have the equipment available to carry this out appropriately.(M19)

“Trying to get sterile dressing packs from anywhere was hard, wasn’t it?... like we’d say we do this every day. So they’d send us ten dressing packs, which is like well that’s ten goes, and that’s got to last us like a month. It’s just not going to work, is it? So we kind of found all different ways of doing it, didn’t we, that...yeah, just as, as sterile as we could be at home without the equipment that they had in hospital.” (M19)

This is one example of how families were expected to provide technical care of a high standard but without access to the resources needed.

No specific equipment was available for many IPC practices, so families improvised their own methods. Specific dressings were available for some devices, such as tracheostomies. However, they were not available in small sizes suitable for children and therefore other dressings were cut into the correct shape.(M3) Families used a variety of different techniques to keep the ends of a central line dry while bathing. Multiple dressings were used in an attempt to form a waterproof seal around the wound site. Sometimes, medical equipment such as gloves and dressing tape were used to create a waterproof cover for the lines.(M2, F7, M8, M11) Non-medical supplies, such as plastic food bags and elastic bands, were adapted to support IPC practices in other cases.

“I remember having conversations with some of the other mums in the kitchen about how they use latex gloves and tie elastic bands around them and somebody suggested easy peel sandwich bags.” (M8)

Families were very aware of the costs of supplies to the NHS and made decisions on how they used equipment on this basis. Some equipment was only used occasionally or was kept in case of emergency, for example replacement gastrostomy or tracheostomy tubes. As sterile equipment, these devices had expiry dates after which they were supposed to be discarded. However, parents made decisions to use these after the expiry date, because they were aware of the cost.(M14)

“And we’ve used expired ones, just because I think it’s a waste to throw them away.” (M14)

The lack of medical supplies meant that families carried the financial costs of providing equipment to keep the device safe.(M8, P20)

“We just tell them plastic bags, cheaper ones that you can just put sellotape around, or get gloves from the hospital and use a glove to wrap round.” (P20)

Some parents felt that the supplies they had available to them did not take into consideration the reality of their daily lives. Families funded additional equipment themselves, taking on the financial burden to provide their child with additional protection against infection. One example given was that syringe caps were not provided. Children required medications at regular intervals throughout the day to be given through their gastrostomy. Families drew up the medications in the morning, either to use at home or to take with them if they went out. However, as syringe caps were not provided, the syringe ends could be left uncovered for hours before being used.(M14)

“The other thing I really wish they would give us as a matter of course, is the syringe caps that go on the bottom because again those are something at the moment that we have to fund ourselves if we want them.” (M14)

5.4.2 Physical environment

In addition to the lack of equipment to carry out device care, families did not have access to the appropriate physical environment to carry out device care. As a result, families undertook complex nursing tasks in the environment of their family homes, which were not designed for this purpose. One example was when parents prepared and administered medications through the device. Some children were on medications which were given intravenously through a tunnelled central line or Portacath. Certain medications were prepared by parents mixing a vial of powder with a specific volume of sterile water and a precise amount of the reconstituted medication injected into the device. This process was expected to be carried out in an aseptic fashion to reduce the risk of infection entering the child’s body through the line. Rather than preparing medications in the relatively calm of a dedicated treatment room, some parents had to get these ready in their kitchens surrounded by their family.(M10)

“You’ve got a small baby screaming at you while you’re trying to do it, it’s different plus you’ve got a kitchen to do it in, as opposed to a treatment room.” (M10)

During my visits to family homes, I observed that feeds and medications to be given through gastrostomies were prepared in the family kitchen. The same preparation areas were used for the family meal and the feed given through the gastrostomy. Family kitchens were busy and chaotic places, which were often used as the primary family room in the home. Children ran in and out, asking questions and interrupting parents as they prepared medications.(M9, M10, M20)

In order to ensure that the care provided to children with an invasive device was safe and appropriate, family homes sometimes underwent significant adaptations.(M3, M6, M9, M11, M12, M16, M19) The changes required to provide safe care for the device included ensuring that there was adequate storage space for equipment and providing an environment for preparing medications. In practical terms, this meant that a child with a device had to have a bedroom of their own. This had potential impacts on the quality of life of the rest of the family: in one family, the parents slept in the living room to minimise the impact on their teenage daughters who would otherwise have to sleep in bunkbeds in a small bedroom.(M12) This family were awaiting the completion of an extension to their home which would provide a more appropriate space for their daughter. A detailed assessment from an occupational therapist had established what facilities were required to provide safe care, including a wet room to facilitate her showering and a dedicated area to prepare medications. Even when there were clear indications from the clinical team of what was required, financial constraints meant that the recommendations of the team could not be carried out. Although a grant was available to make some adaptations, the money available was not sufficient to carry out all the work required. The family had to make a decision between moving house (which would mean changing schools for their other children), carrying out the additional work at personal expense to themselves, or carry out the work covered by the grant and compromise the environment in which care was provided.

“So their lovely plans of actually what ideally she should have haven’t happened, because we can’t afford to pay the difference [...]So the practical was we built what we could afford, we build a lounge, she has a bedroom and we forgo the wet room and their funky high-tech medical room and things.” (M12)

The building work associated with the adaption of the physical environment was disruptive for families. I witnessed this disruption at first hand during visits to family homes (families 11 and 12). The work could involve a major re-structuring of the home, and could go on for several months. As a result, families had limited access to the parts of the house which were being adapted. In one home I visited (family 11), there had been delays to the building work and disagreement about the funding arrangements after the work had started. At the time of my visit, the family had limited access to their kitchen which was filled with building materials, and the house was cold because an external wall had been demolished. This disruption had been in place for several months by the time I made my visit to the family, and the work had still not been completed eighteen months later. Throughout all this time, the family continued to care for their son in the home and in an environment which was not suited to the delivery of technical care.

5.4.3 Human resources

Caring for the device involved a daily routine of checking and cleaning to keep it free from infection, thus carrying out IPC measures meant a significant time burden for families. Everyday activities such as bathing became prolonged because of the additional care required to maintain the device safely.(M2, C12, P8)

“The whole process of even bathing before we even get into the bath takes a good fifteen to twenty five minutes to make sure they are secure and clean and dry.” (M2)

The additional time required to keep the device clean had implications for the child’s care. A child who was tired could not simply be put straight to bed because of the need to clean the device. Parents had to keep their child awake so that they could carry out device care, even though both parent and child were distressed as a result.(M3)

“If she’s tired in the night, it’s the worst thing to try and do that.” (M3)

The time spent on IPC practices impacted on the precious time that families could spend together. Families had to begin bedtime routines early so that there was time to accomplish all the aspects of device care, thus there was less time to spend with the

child. If device care was not completed in a timely fashion, then children went to bed late, and parents had less time to spend alone or with other adults.(M6)

“If you’re not down by eight it’s going to be after nine before he goes to bed, and you’re thinking my evening, my evening.” (M6)

Although part of everyday life and routine care for the child, carrying out IPC measures was often a balance between ensuring safe device care and time for other activities of daily life. One mother explained that there could be a conflict between maintaining the device and other jobs that had to be undertaken, such as taking her son to school on time.

“A few times at half eight in the morning when you are saying ‘get your shoes and coat on’, he goes I need a new dressing. At which point I am ready to climb the walls and am thinking why couldn’t you have mentioned that half an hour ago.” (M8)

Families had to choose whether to focus their time and energy on device care, or on the other tasks required to sustain normal family life.

Some procedures, such as cleaning around gastrostomy sites, could be carried out by a single individual. Others required additional pairs of hands. One example was when a tube inserted into the tracheostomy site had to be changed. Tracheostomy tubes were secured around the neck by tapes which were supposed to be changed regularly. Ideally two people (at least) were needed to perform this safely: one person would hold the tube in place while the other changed the tapes securing the tube. This was particularly important as children were dependent on the tube remaining in place to keep their airway patent, and in order to allow them to breathe.

“It’s really hard to do on your own, really hard to do.” (M6)

Technical difficulties in performing this task meant that it was delayed or omitted by families. One mother explained that she had been advised by professionals to change the tracheostomy tapes every day to keep them clean. The mother explained that changing the tapes was a technically challenging procedure. She had made a decision

that the tapes would be changed on a weekly basis, at the same time as changing the tracheostomy tube.(M3)

“I mean, their policy was, as well, that you change her tapes every day. Well, I don’t do that. I change them weekly when I change her tube. ’Cause, to me, changing just the tapes is harder than changing the lot because you’ve got to fiddle with two sides, so we don’t do it.” (M3)

This mother made the decision that she did not have the resources to change the tapes every day without adding significantly to her existing workload. The availability of people to carry out device care influenced how families followed guidance from healthcare professionals.

Carrying out device care became even more complex when children had additional care needs. One child had contractures in his neck and was unable to hold his head out of the way of the tracheostomy tapes when they needed to be changed. Three people (his mother and two carers) were needed to carry out this procedure every day.

“You have to have someone to hold his trachy, and then someone to move his head away, so that then you can change all his dressings and change his tapes. So that’s three people every morning to change tapes.” (M19)

This boy also had had a tunnelled central line in position, which had then been removed. The position of the line made keeping it clean very difficult, especially as the boy was unable to lift his arm out of the way to expose the entry site. Instead of a dressing change being carried out by a single carer, two people were required because of his additional needs. Without this assistance, the line could not have been kept clean.

“You wouldn’t be able to do it on your own.” (M19)

Families depended on professionals to provide them with support. If this broke down because of staff shortages or illness, then parents had to cope alone. They were left to decide if it was safer to attempt the device care alone, or to omit it and put their child at risk of developing an infection. One mother explained that she relied on the assistance of community nurses to assist her with changing her son’s tracheostomy tube. Visits

from the community nurses could be cancelled at short-notice, leaving the mother without the support needed to change the tube. The mother had to decide between trying to change the tube alone, or delaying the tube change until the community nurses were available to help.(M10)

“There were many times when I would just delay it by two or three days and wait for the next available pair of hands.” (M10)

The need to provide device care was a significant use of families’ precious time. The absence of support from professionals or family members meant that families faced difficult decisions about the care that their child received, adding to their burden.

5.4.4 Families develop their own expertise in managing technical conflicts

Families gradually became more confident in the care of the device, making more independent decisions as a result. When the device was first inserted, parents relied more on the advice of trained professionals.(F7, M16) As time went on, parents became more confident in their care of the device.(M6, M11, M16, M19, M20)

“I mean I think probably we take more risks now.” (M6)

“I’m sure I followed the rules far more in the early days.” (M11)

The workload that parents took on increased over time; professionals might take a step back as parents became more confident in carrying out device care. A mother described how she had started changing central line dressings and cleaning the site in hospital under the direct supervision of nurses. After discharge, the community nurses had initially supported her to change dressings over the central line. After some weeks, she became more confident and performed the dressing changes herself.(M2) Another mother explained how she had become more confident in her ability her daughter’s device care, to the point that she now rarely contacted her community nurse for advice although the continued support was very important.(M14) As time went on, and the child remained well, families developed more confidence in their decision-making.

“I think what I’ve done is kept him alive for 10 years, so I will stick with what I have done, as long as there’s no great objection to how I’m doing it then it’s, should be alright. I think that comes with time though.” (M6)

Families gradually developed their own boundaries about what risks were acceptable to them. One family had two children with gastrostomies. The mother described how the family had initially followed the instructions for gastrostomy care very carefully, restricting their sons’ activities as a result. Their sons had previously enjoyed playing in a sand-pit in the garden, but when the gastrostomy was first inserted, the parents had stopped their play. The children then began to play in the sand-pit with additional coverings to protect the gastrostomy site – the device-site was covered in waterproof dressings and vests. As time went on, and the children remained healthy, the parents became more confident and relaxed their precautions. By the time of my visit, the children were playing in the sand-pit without any additional coverings.(M20)

“When he first had it [gastrostomy] it was all cotton wool and boiled water, now that he’s had it, he gets normal baths and he goes swimming.” (M16)

Going for a long time without developing infections further reinforced to families that they were caring for the device appropriately, and gave them more confidence in their ability to care for the device.(M17)

“We must have been doing something right, because we’ve managed the whole year without infection.”(M17)

Families used their knowledge of the child and their device to assess when additional care needed to take place. One mother described how she assessed the appearance of the gastrostomy tubing to determine whether the tube needed replacing.(M15)

“I was looking at it today when I took those photos, thinking oh, looks a bit manky, maybe I should change the end of it. (M15)

Rather than seeking medical advice for all complications, families became more adept at judging which situations they could manage themselves, and which needed specialist advice.(M14, M19)

“We’d probably try and tackle anything in the main instance.” (M14)

Some families who built relationships with professionals felt that their skills were recognised, and that they were acknowledged as competent carers. As a result, families had more flexibility over care plans and the support that their child received. One mother felt that this trust in her by the medical team had facilitated her decision to reduce her son’s care package as she was considered able to carry out his care herself.(M19)

“All the medical professionals that know [child] and I well, know that I’m perfectly capable of doing all of [child]’s care.” (M19)

The expertise that families developed allowed them to carry out device care in a way that fitted with their everyday lives while still providing the care that the child needed.

5.4.5 Develop expertise in recognising and managing infection

Families became adept at recognising warning signs of device-related infection in their child. Some parents relied on frequent objective measurements, such as temperature measurements, to highlight any signs of infection. Other parents used their knowledge of their child to decide if they were unwell.(M12)

“I know some of the PN [parenteral nutrition] mums check their temperature everyday regardless, but then you’re just going to find things you don’t want to find” (M12)

Some professionals supported families to develop the individualised expertise needed to work out when their child had an infection.(M16, M17) One mother explained that she had initially been unsure if the redness and discharge around the device was a sign of infection or not. She spent the first few months asking the community nurses to review the device site with her, explaining which features would indicate an infection. Eventually, with the support of the community nurses, the mother learnt to recognise the signs of infection herself.(M17) Another mother explained that when her son first had a gastrostomy sited, she had been concerned every time the skin looked red or if there

was some bleeding or discharge. Now, she felt confident assessing the device site, and managing these concerns herself.(M19)

“To start with you’re watching it all the time... Panicking all the time. And now it’s just get some more dressings and give it another clear.” (M19)

As time went on, parents began to recognise the signs of infection themselves. Rather than waiting for professionals to inform them that their child had a device-related infection, parents were constantly on the look-out for any changes to the child’s device site which could indicate an early infection. Parents could then trigger interventions from healthcare professionals, or manage the issue themselves. Families used their expertise in device care alongside their knowledge of their child to formulate a management plan. One mother explained the approach she took to a possible infection around her daughter’s gastrostomy site. (M14)

“I’ve had it swabbed, I’m waiting for results to come back, but in the meantime I’m using the various lotions and potions that we stock to treat it” (M14)

In this example, the mother made an assessment that her daughter had a possible infection; she also made an assessment that her daughter was well enough to stay at home and did not require urgent medical attention. By guiding the process in this way, the family were able to control the impact that possible infection had on their family life while still getting care for their child.(M14) Acting independently meant that families were able to limit the spread of infection and the impact that it had on the child.(M18)

“I dealt with it straight away... got the antibiotics, and it was kind of gone before it had started” (M18)

It was also important that parents identified issues that were not related to infection. This meant that families were not rushing to seek medical advice unnecessarily.(F1) Parents looked at the device site to establish if there was any fluid weeping from the site, or redness around the area. Events during the day that could have affected the device site were carefully considered (e.g. some gastrostomy sites would discharge clear fluid after the child had been swimming). Parents used all this information to judge if

the changes around the device site indicated an infection or not.(F1, M15, M18) One mother demonstrated this to me during the data collection:

“See it’s a little bit crusty (cleans around gastrostomy site) yeah, that just cleans off. It’s quite, not granulation actually.” (M16)

These examples demonstrate how parents use their experience of caring for the child’s device to assess if an infection is present, and to make sophisticated management plans to prevent the infection worsening.

5.4.6 Families share their expertise with peers

Families of children with invasive devices shared information with each other about the care of the device. Such information was valued because it reflected the realities of life with a child an invasive device.

“It has to be real experience. It has to be parents talking to parents and discussing this is what happened to me.”(P8)

Although families received advice from healthcare professionals about the IPC measures that should be followed with device care, there was little practical information about **how** this care could be delivered in the home. One mother explained that she had been advised to keep the central line dry when her son had a bath but she was not given any advice about how she could achieve this at home.(M8) Another mother described how she had left hospital with little appreciation of what having a child with an invasive device would mean for her daily life. At the time that her daughter’s tracheostomy was inserted, she had a small baby that was only a few months old. She described how she was unable to leave home because she was unable to carry the equipment needed to care for her daughter’s tracheostomy as well as the baby. Although she had received training in the care of the device from professionals, there had been little to prepare her for the reality of life with a child with a tracheostomy.(M3)

“You’ve got to find it all out for yourself or from other parents. I mean, I’ve learned more from other parents than I have from any, probably, professional.”(M3)

For some families, their first contact with an invasive device came through the experience of other families during a hospital admission. This was particularly true of children with cancer who were usually admitted onto a specialist oncology ward. Families who were new to the ward observed children and families around them, learning about the devices and how they were used.(F5, F7) During one hospital admission, the mother of one child found that parents met in the kitchen of the ward, and discussed aspects of their child's care. Parents discussed their concerns about device care and shared solutions that were tried and tested. As a result of these conversations, the mother discovered an alternative method of keeping a central line protected which she would not otherwise have learnt about.(M8)

"I remember having conversations with some of the other mums in the kitchen... it is the hints and tips about ways of doing it which I think would have been invaluable." (M8)

The experiences of others helped families develop techniques for managing IPC. Families took advice and suggestions from others, but adapted the advice to form their solutions which worked for them and their child.(M11)

"That's generally the best way of doing it, is finding out what works by using some intelligence, but trial and error is better than anything else." (M11)

Families used these networks to share information about treatments for infections. One example of this was in the management of gastrostomy site over-granulation and subsequent infection. Some families used a topical ointment around the gastrostomy site. Families learned about this treatment not through their clinical teams, but through other families sharing their experiences on social media.(M10, M16, M18)

"We use Maxitrol ointment, which is antifungal, antibacterial, steroid, works brilliantly. Wasn't referred to us back here, I found out about that online, a child in Southampton who'd been prescribed it for their PEG. And I mentioned it to the GP who said alright, we'll give it a go. Works beautifully whenever he gets sore." (M10)

This is an example of how families shared technical knowledge through informal networks to influence the clinical care that their child received.

At home, families shared information amongst themselves about the services that they had access to. Families experienced variations in care and support, and were often unaware that they could have more help – sharing information about the care that they experienced encouraged other families to seek out services and equipment that they would otherwise have been unaware of.(M6, M11, M19) Social media sites, such as Facebook, provided forums for parents to share their concerns and experiences.(M9, M10, M11, M16) Without these networks, families felt that their child would not receive optimum care as they would be unaware of the treatments available.(M16)

“You find things out by chance meeting with different doctors, or mentioning something that somebody else knows...you struggle for years and then someone goes, but why don’t you use this?” (M16)

Some families were encouraged to form peer networks by professionals. One mother explained that she had been introduced to parents of other children with similar health conditions by professionals. In one case, a family with a child with an invasive device had visited her daughter’s school. When the family asked about the school’s experience of gastrostomy care, the school staff had explained that they already supported a child with a gastrostomy, and facilitated an introduction between the two families. In another example, her community health visitor had supported the introduction.(M14) Two of the families in the study had been introduced to each during a hospital admission by their consultant.(M17) Families received information from professionals that had originally come from other families.(M1, M8) In this way, professionals could act as a conduit for information, allowing them to screen the information that families received.

“they [community specialist nurses] have talked to so many parents that are in exactly the same stage you are at so they have got all that knowledge in their heads” (M8)

Not all families had support from informal networks. Some parents found that they were relatively isolated from other families in a similar situation.(M16) Others tried to form

links on social media or group pages, but found it difficult to build relationships without meeting people in real life.(M17) Some issues discussed in informal networks could be alienating for inexperienced parents: experienced families sometimes used technical terminology which new families struggled to understand initially, and discussed issues which could seem overwhelming.(P8)

“You are in a whole different world of language. You are also in a whole different world of consequences” (P8)

Professions had mixed views about the networks that families formed and the information that was shared between them. Some professionals recognised that families benefited by sharing their experiences between themselves and supported the development of informal networks by introducing families to each other.(P2, P9) One specialist nurse explained that by introducing families to each other, she was able to facilitate an additional level of support that would not otherwise have been available. She saw this as part of her role in supporting families.(P2)

“Some families need to be introduced to other families... that sometimes sets off this conversation so they have got support from that side as well.” (P2)

“I think that’s the best way of parents coping, is just being with other parents who are in the same situation as them” (P9)

Other professionals were concerned that the information from families would be incorrect or misleading.(P10, P12) One nurse expressed concern that families only sought advice from peer networks because they were unable to access professional advice.(P12) The information that families shared between themselves was seen as having lower status than information which came from professional sources.(P10)

“They tend to stick to what the nurses, they know it’s the right advice... from the nurses it is the gold standard.” (P10)

5.5 Emotional trade-offs

Carrying out device care placed a significant emotional strain on families. Device care made children different from their peers, and led to social isolation of children and families. The need to maintain device care made significant changes to everyday life which families felt ill-prepared for.(M3, M10, M11)

“Families literally, they find out their child needs a feeding tube or whatever, then they have one put down and they’re sent home, and suddenly they’ve got syringes and feeding bags and pumps and the whole house is filled with medical equipment, and they’re just completely disrupted.” (M11)

The emotional consequences of device care were poorly recognised by professionals and families had little support to deal with these burdens. One mother explained that the focus of the clinical team was on exclusively on her son. She felt that there was little consideration of the emotional impact on family network who were expected to provide device care.(M10)

“But the casualties are invisible, and they tend to be the families behind the patient.” (M10)

5.5.1 The parent as a carer

Parents undertook everyday device care for their child as outlined in chapter 3. Taking on these aspects of care meant that parents had to be both carer and parent for their child. The two roles placed competing demands on parents – a phenomenon known as “role strain” which is well described in parents of chronically ill children.(164) One mother expressed that providing device care made her more of a carer and less of a mother.(M11)

“I hated the fact that was affirming me not being a mother.” (M11)

Parents struggled to cope with the demands of performing technical device care while providing emotional support for their child. Taking on the role of carer meant that some parents could not express their own distress. One mother described how her child became upset during gastrostomy button changes, but that she was unable to

acknowledge her own feelings about the procedure because she had to carry out the procedure.(M14)

“I couldn’t cry in front of her, I couldn’t do any of those things, I had to be the mum that was in control... you move over from just being a parent role to suddenly being much more medicalised.” (M14)

This mother explained that the desire to provide her child with a more normal life was her primary motivation for carrying out aspects of device care that could otherwise have been delegated to professionals. She felt that she was the primary carer for her daughter and that it was her role as a parent to take on the majority of her care where possible.

“She’s my daughter, she’s my child, so I want to do what’s right for her, what’s best for her. I don’t want her completely medicalised, so if you love your child you’re going to do it.” (M14)

In this case, the mother’s role as parent contributed to her taking on the additional responsibility of the care role, even though the two roles were in conflict.

Another motivation for parents to take on device care was to minimise the distress to the child. Some parents felt that when a trusted individual, such as a parent, carried out device care, the child experienced less distress.(M10, M11) One mother explained that she had learnt to carry out technical aspects of device care, such as using a Portacath, because it meant that her child was less distressed by the procedure. As a result, the mother experienced more distress herself.(M10)

“That put pressure on me, but equally it reduced pressure on [child].” (M10)

This mother explained that she felt that if she undertook the care of the device, then this would provide the best possible care for her son, and the pressure on her other children would decrease as a result. (M10)

“All been done out of a mother’s love and a desire to keep the rest of the family running.” (M10)

Role strain was evident in parents who were also trained healthcare professionals. One mother who was also a children's nurse explained that she was already trained to use a central line and gastrostomy because of her work. She was able to provide technical care at home for her daughter, such as taking blood samples from the central line. As a result, the family could spend more time at home without having to go to hospital to have blood samples taken. Despite the advantages, this mother felt that providing this care hindered her from fully carrying out her role as a mother.(M12)

"Sometimes it's handy... and other times think I just want to be mum." (M12)

The care of a child with an invasive device was seen as an extension of the parenting role in many families.(M10, M11, M12, M14, M15) When parents did access support and help in caring for their child, they sometimes felt guilty that they were unable to provide this care themselves.(M15)

"I still go through the guilt of having so many people help me, I don't look after my family, somebody else does." (M15)

Other negative impacts were also evident. One father expressed his fear that his son would grow to dislike him because of the medical care that was carried out. The child had a Portacath in place which needed very little ongoing care, and a community nurse visited the family every month to flush the device. As a result, this father could choose not to carry out device care. He did not want to learn to use his son's Portacath as he felt this would mean that he was carrying out a potentially traumatic procedure which would damage his relationship with his son.(F4)

"I just want to be his normal parent, whatever that kind of means, and other people come and do medical stuff, but I don't really want to be someone that he sees as someone who comes and does medical stuff, I'd rather that he dislikes the nurses and the physios and the doctors and all that." (F4)

Another mother explained that she had refused to learn to give medications and feed through her son's central line, despite considerable pressure from the clinical team. Her son had gastrointestinal problems and struggled to absorb feeds. During his admissions to hospital, her son was reliant on PN until his gut recovered enough that he could

absorb his usual gastrostomy feeds. The clinical team felt that if the mother learnt to use the central line, then the child could be discharged home sooner. Although the mother wanted to take her son home, she felt that she would not be able to cope with the strain of providing highly-specialised central line care in addition to her existing workload.(M11)

“Every time he had problems after an operation they always said well you need to do PN training. And so I fought and fought and fought, but I knew if I did the line training that I would lose the battle. Because while I was blocking a bed, they would work with me to try and get the feed restarted, because they wanted the bed. But if they could have kicked us home, with me doing all of the stuff they were doing in hospital, they would have done. you know, and so I said to them I could just about cope with the care he needs now, you know, if you then expect me to do IV meds all through the night, and to do PN I will actually crack. You know, I have two other kids as well, I don’t spend enough time with. That is taking it beyond being, I could never be his mother, I’d spend my whole life being a nurse, I’m not prepared to do it.” (M11)

This example demonstrates how the pressures of carrying out technical care can erode the ability of parents to fulfil their parenting role.

5.5.2 Carrying out IPC practices makes children different

Carrying out IPC care and maintaining the device safely marked children out as different from their peers when they were engaged in everyday activities. One mother explained that she had taken her two sons with gastrostomies to the beach. The gastrostomies were covered with waterproof dressings to prevent sand and seawater from coming into contact with the device site. Despite this precaution, the mother was concerned that if the children entered the water, then the device would become contaminated. The mother continually reminded the children to stay away from the water’s edge.(M20)

“And we spent the whole time, you know, saying to the eight-year-old, no further, be careful. People are probably thinking what!?” (M20)

The restrictions on the children's play at the beach highlighted their difference from other children.

Children relied on their parents to assist them in caring for the device. The need for parental support was another aspect of device care which marked children out as different. One older child was only able to participate in school trips away if his mother accompanied him to help with bathing. While the other children were becoming more independent and spending time away from their parents, he was still reliant on his mother being there to take care of his central line. This child was especially concerned that his schoolmates would find out about his central line, and tried to hide it wherever possible. Hiding the device made it even more difficult to ensure that infection control was maintained outside the home.(M8)

“So he was creeping along the corridors in the evenings, when everyone else had lights out, to come and have a shower in my room because he didn't want anyone else to see it and then creeping back again so that nobody knew that I had to dress it and sort it.” (M8)

Children in this study suggested that they were “othered” – thought of as different from other children – because they had an invasive device in place.(252) Having a device made children different from their peers because of the restrictions that the device placed on children's participation in the social world; they were also made different because of the psychological impact of having a device. This had implications for infection control practices, as it affected how device care was carried out. An awareness of difference from their peers also affected some children's confidence, and their willingness to participate in self-care activities.

5.5.3 Isolation as a result of IPC

Infection control practices had an impact on the social interaction between the child, their family, and the wider community. This added to the isolation that many families experienced.

Fear of infection meant that interactions with the outside world were limited. This included staying away from school. Parents were concerned that contact with numerous

other children would increase the risk of infection to their child. They had experience of trying to send their children to school, and the result had been repeated infections. This was an example where families had to make a difficult decision between the risk of infection and the possible benefits to their child of interacting with others.(M12, M19)

“At school you’ve got all of the, all the children and all of their families, and any infections that they’ve got going on in all of their families. Then you’ve got all the staff, and then you’ve got the people that are coming in and out of school every day, people doing deliveries and suchlike, people come for meetings, all of those people are an infection risk.” (M19)

When parents did take their children into the wider world, the threat of infection meant that parents had to be extra vigilant. This took time and energy, and meant that parents found it difficult to interact with other families.(M10)

“All those times I would have gone to soft play with all the equipment, and I wouldn’t have had a moment to think about talking to another parent.” (M10)

In situations where children and families could meet others with shared experiences, infection control practices also impeded these interactions. Children were often admitted into a cubicle rather than into the bay, and were kept in isolation in order to protect them from infection. A girl described this as being *“like a goldfish in a bowl”* because other patients and families kept walking past the windows and looking in at her.(C12) The physical isolation restricted informal interactions between families who were genuine peers, and added to the feeling that children were different from their peers.

5.5.4 Loss of independence

The importance of maintaining IPC meant that children with invasive devices now required assistance and supervision during daily tasks that they had previously performed independently or with minimal assistance. One example was bathing. Rather than have a shower independently, children with central lines needed their parents to

help ensure that they line stayed dry when they bathed. The reliance on their parents' assistance was a backwards step in children's independence.(M2)

"I am having to do what I did when he was a toddler and go in and supervise everything. Obviously while he was in there I would be around anyway but it was up to him to wash himself in the shower and now I have to supervise and make sure it is not wet." (M2)

Concerns about device care meant that children were rarely left alone. Care of the device was specialised, and usually confined to a few family members. As a result, children with invasive devices spent a lot of time in the company of their close families. The difference between a child with a device and their health peers was not so obvious with younger children who ordinarily spent more time in the family circle. As children grew older, the difference between them and their peers or siblings became more apparent.(M12)

"My friends have got children that are of the same age, are now getting to the point where they don't need someone at home all the time... whereas we don't see that progression, because obviously [child] needs someone with here all the time." (M12)

Children with invasive devices were unable to develop the autonomy that their peers would have at a similar age, further limiting their normal childhood development.(122)

5.5.5 Managing the pain associated with device care

IPC practices were associated with pain for the child. This was usually in the everyday care that parents provided to children, such as changing the dressings over a central line site or cleaning around a gastrostomy. Families were thus very aware of the distress their child endured, and some children felt that the pain was the most difficult aspect of having an invasive device.(C2)

"If it didn't hurt... it would be easy." (C2)

For some aspects of device care, the child's role was, as described by parents and professionals, to accept the care given. Children were expected to submit to having central line dressings changed, or having a needle inserted into a Portacath. Compliance with aspects of care, even though the experience was painful and distressing, was part of the child's "work".(M1, M14, C12)

"She knows she has to have it done." (M1)

The severity of the pain and its impact on children made it difficult for parents to carry out IPC practices. Nonetheless parents felt that they had to undertake these procedures regardless of the distress caused to their child.(M1, M9, M14)

"There are things that she will say to me please don't do it, please don't do it, the button change being one. And I know I have to do it, it's not a question of being unkind, or, or, you know, not loving her... it has to be done." (M14)

This pain could be so bad that some children had to be physically restrained by their parents in order to carry out dressing changes and skin cleaning.(M2,M10)

"I had to restrain him in certain positions, in order for them to be able to just change the dressings." (M10)

Despite attempts by parents and children to reclaim some control over the device, this remained largely an illusion. The dressings must be changed; gastrostomy buttons replaced; and device sites cleaned against the wishes of children themselves. As children realised this, they used increasingly desperate strategies: pleading with their parents to delay the intervention; running away from parents and professionals, fighting back as they were pinned down.(M2, M14, M17)

"He hid in the corner and was holding on for dear life and I am having to physically rugby tackle him and again without hurting him and of course I am sobbing and he is sobbing."(M2)

To try and minimise the pain caused to the child, parents would delay changing the dressings over the central line site if they felt that the child was too anxious or

distressed.(P20) This attempt to minimise pain also affected general hygiene and bathing. In order to avoid the dressing becoming wet (and thus requiring more frequent changing), children avoided showering in between dressing changes.(M2) Parents tried to maintain the routine of cleaning and dressing the insertion site at the same time as minimising the distress to their child.

Cleaning a gastrostomy site could also prove challenging as moving the gastrostomy could cause pain which made children reluctant to allow their parents to clean the site thoroughly.(M17)

“We try and push it, but [she] doesn’t like it when we move it aside” (M17)

Another child experienced so much pain that his mother had to wait until he was in a deep sleep before carrying out skin care. She would then creep into his room to try and clean the skin around his gastrostomy and apply a barrier cream without waking him up.(M9) Changing the gastrostomy tube was a less frequent, but still traumatic event for the child. Children recollected these events as painful and were apprehensive of future procedures.(M9, M14, M17, M18) Button changes could be delayed as a result.

*“It was like a week, week or two longer, because she wouldn’t let me do it.”
(M17)*

This is one of the examples of the decisions and actions that parents make in everyday life in order to achieve the best outcome for their child.

Some children were left so distressed by the repeated pain caused by device care that they required input from play specialists and psychologists to be able to tolerate IPC measures.(M10, M14) Families reported that the extent of this pain was not always well recognised by healthcare professionals.

“We’ve been told by various community nurses it doesn’t hurt, it’s not a problem, it just feels a bit uncomfortable.” (M14)

Parents were more prepared to accept that the pain was multi-factorial, and that apprehension played a significant part in how their child experienced device care.

Rather than dismiss the pain as unimportant, parents acknowledged that fear of device care could exacerbate the pain that the child experienced.

“She gets anxious... she anticipates it going in, so everything goes tense, which makes it harder.” (M18)

Strategies included having carefully planned patterns for interventions in order to manage the anxiety and distress around device care. Nonetheless healthcare professionals did not always appreciate the importance of following these routines, and the hard work to overcome the child’s fear was undermined.(M10)

“We had it under control for a few months, that he was responding well to the procedures we were doing... they’d said they’d had to access it for an emergency. It wasn’t really an emergency, they should have called me to go over and I’d have gone back over to them, but they couldn’t be bothered to wait for me basically... And they did it, and that was it, he was broken again after that, and we never really clawed it back.” (M10)

The pain that children experienced had a direct impact on device care provided by families which was poorly recognised by professionals.

Pain also affected the care of suspected infection. Children were reluctant to allow their parents to inspect the device if it was painful. Device-site pain could be a sign of infection, therefore it was important that the device was checked. One girl had a gastrostomy site infection and complained of pain around the area, but was reluctant to let her mother examine the gastrostomy or to seek further advice.(M17) Families had to balance the risk of physical harm to the child against the psychological impact of loss of control. This is one example of the emotional labour that parents performed in the everyday care of the device. Families recognised that it was important that the child retained some control over the care of the device, and their bodies. They were aware of the psychological impact on their child that resulted when this control was lost. This was an important consideration when the needs of the child were at odds with the need to care for the device. A child’s need to maintain jurisdiction over their own body could

limit the care that families were able to give. For example, the child could refuse to allow their parents to inspect the device, or to check for any injury:

“She kept saying it hurt but she wouldn’t let us go near it and she didn’t want to go to the hospital.” (M1)

5.6 Summary

In this chapter I have explored how children and families experience device-related infection and the significant impact that such infections have on their lives. As I described in Chapter 4, normalisation was a key motivator for families in children with invasive devices. Device-related infections posed a significant threat to the everyday lives of children and their families. Device-site infections were painful, restricting children’s participation in activities and stopping them from sleeping peacefully. Although such infections had a significant impact on the child’s quality of life, the child was usually treated at home. Suspected CLABSIs resulted in emergency hospital admissions which were unpredictable and highly disruptive. Normal activities, such as going to work, were set aside as children were rushed to hospital. Special family events, such as birthday parties and holidays, were postponed or cancelled at short notice. Families feared the consequences of CLABSIs – some of the children in this study had experienced significant bloodstream infections; other families had heard of children who had been seriously ill or died as a result of CLABSI. Device-related infections imposed multiple burdens on children and their families.

Thus families in this study were highly motivated to minimise the risk of device-related infection. They were also highly aware of the work that was involved in maintaining device sterility. Children and families described in detail the work of minimising the risk of device-related infection which was a part of everyday life. These IPC practices took a great deal of time and effort on the part of families. Care was made more challenging as families often lacked the resources to carry out procedures effectively. Families attempted to integrate IPC into family life, although this resulted in additional labour. Carrying out IPC could further emphasise that the child was different from their peers – a further example of the stigma associated with the invasive device. The work of carrying IPC practices threatened the normal life of the child and their wider family.

As I describe in Chapter 4, families felt that device-insertion facilitated the normal life of children by minimising disruption resulting from medical care. Device-related infections threatened the normal lives of children and families; IPC measures which aimed to minimise the risk of infection imposed burdens on families which also threatened the process of normalisation. Families made difficult decisions as they tried to balance the demands of maintaining IPC against the impact that this care had on the child and wider family. Rather than simply a series of tasks to be performed, maintaining the device safely was a complex process of managing trade-offs that was inherent in completing this work. I explore how professionals work with families to support these endeavours in Chapter 6.

6 Professionals' role in supporting children and families at home

I start this chapter by describing how professionals support IPC measures, and the effect that device-related infection has on them. I then explore how professionals acknowledge and recognise the work that families undertake to provide device care. I conclude this chapter by giving examples of how professionals and families work together and consider the different influences on partnership working in preventing device-related infection.

6.1 Professional role in infection prevention and control

Clinical professionals recognised that they had a role to prevent device-related infections. Like the families in this study, professionals described IPC as one of many competing priorities which took place alongside other aspects of care. Maintaining IPC and device safety meant that professionals, as well as families, were continually engaged in a series of complex trade-offs as they tried to support families. In this section, I provide some examples of how professionals viewed their role in maintaining IPC, balanced against their other roles and when they had other priorities.

6.1.1 Choice of device: central line or Portacath?

Professionals could influence the risk of device-related infection by the advice they gave to families concerning device insertion. In some cases where a device was needed, families and professionals had a choice of different devices. This was the case for children who needed to have central venous access, which could be achieved either via a central line or an implanted device such as a Portacath. Professionals recognised that the choice of device was important to minimise the risk of infection, for example when choosing a form of central venous access. Some professionals viewed Portacaths as preferable to tunnelled central lines, because they were seen as less likely to become infected from external sources.(P3, P13, P18)

"Ports are a lot harder to lick into and have your dog snot on." (P13)

"But the portacaths get infected less because again they are not hanging out, they are not touching the skin, not in nappies, not in places they shouldn't be, so they don't get covered in poo." (P20)

Despite their advantages, not all professionals advocated Portacath insertion as there were concerns that the child would be distressed during use. As I describe in the previous chapters, much of the daily care of the central line took place away from the hospital and thus was not witnessed by professionals.(P2, P3, P13) In contrast, Portacaths were usually accessed by nurses. Using or “accessing” the Portacath meant that needle-tipped catheters were pushed through the child’s skin which was numbed using anaesthetic cream, causing a physical breach in the child’s body. Some nurses found this process traumatic, particularly if the child was also distressed by the procedure.(P1, P14, P20)

“Doing some accessing of ports can be really quite stressful.” (P1)

Professionals had a role to explore the choice between central-line and Portacath with the family.(P2) However, the professionals who advised families on the choice between central lines and Portacaths were also stakeholders in the decision that families made.(191) The nurses who were distressed by accessing Portacaths in this study were based in the hospital, and were not privy to the distress that children and families experienced as a result of the daily care associated with a central line. Their preference over choice of device may have been influenced by what they saw and experienced, rather than the unseen experiences of families.

6.1.2 Risks during care provision

Professionals faced challenges to ensure consistency of infection control practices while providing care to children. In some cases, carrying out one aspect of care meant that compromising infection control practices and left the child at risk of infection. For others, IPC was not the sole priority when providing care to the family. Trade-offs were a part of professional practice.

One example was checking the catheters of a central-line which were clamped when not in use. Day-care and community nurses described that the contact with a family was an opportunity to inspect the device to ensure that it was safe. Clamping the line could produce a kink which meant that blood could stagnate in this part of the line, or clot. This also weakened the line in this area, increasing the chance of its cracking. Cracks in

the plastic of the catheter breached the sterile system and were a potential source of infection. The risk was increased for lines which had been in for some time. Regularly inspecting the line meant that problems could be detected early, before the line broke or infection took hold.

“We need to have a look at the line when they are here, even if they are just here for clinic.” (P2)

Each encounter with professionals was an opportunity to review the device, although one community nurse felt that device care was not always a priority for professionals.

“I really don’t think we look after lines. We don’t clean them, we don’t check them for splits.” (P17)

In hospital, professionals tried to avoid disturbing children and families when they were asleep. Nurses were unable to see the line clearly when the lights in the room were off, and they were unable to move the child into an optimal position without waking him/her up. They sometimes sought to minimise the distress to the child that would arise from waking them up, even if this increased the risk of developing a device-related infection later on.(P13)

“I think we’re like oh, we’ve done the right thing, because the child’s no longer distressed and line-infections don’t happen that often, and we are always clean.” (P13)

Other problems arose when central lines were accessed purely to take a blood test at a time that was convenient for the professionals. Using a central line or Portacath breached the sterility of the device and increased the risk of infection. Reducing the number of times a device was accessed was part of IPC practices in some areas, such as paediatric ICUs where access to an indwelling device was restricted and professionals coordinated when the device was used.(P13)

“PIC [Paediatric Intensive Care], they won’t take bloods unless they’re already going in to a line to give drugs.” (P13)

This practice was not universal as one junior doctor explained. In different departments, lines could be accessed several times if other clinical needs arose.

“I don’t think we’re as good as we can be about rationalising our line use.” (P13)

Sometimes, attempts to minimise infection from one source could increase the risk of a device-related infection. Children with significant immunosuppression as a result of chemotherapy were at risk of developing a significant fungal infection. As a result, they were often started on anti-fungal medication, given three times a week through a central line. By giving a prophylactic medication intravenously, the line was breached more often than it would be otherwise.(P17)

“You are giving ambisome [anti-fungal] for prophylaxis but, at the same you are then accessing that line so much more than you would need to normally.” (P17)

Community nurses in schools did not always have access to facilities to ensure that infection control was maintained. Device care had to be carried out in the same room as a sink so that the nurse could wash their hands before carrying out device care. Few schools had spare rooms with these facilities, so nurses used whatever space was available. Sometimes this meant that devices were used in the back of busy classrooms, or in toilets.(P11, P17)

“You have to have somewhere with a sink, so sometimes it is like the staff room with the toilet or the kitchen area.” (P17)

If the care was not carried out in these spaces in the community, then the child would have to go to hospital or risk missing important treatment. Nurses chose to carry out care in sub-optimal places to minimise the impact on the child. Professionals felt that their role was to manage these trade-offs to ensure that the child was safe, while minimising the disruption to their normal life. In this way, professionals were engaged in supporting families’ attempts at normalisation.(162)

6.1.3 Number of people accessing the device

Professionals felt that the more people who used a device, the higher the risk of infection, regardless of whether professionals or families were involved. When a small

number of people used a device, it was easier to ensure that a consistent approach was used. This was particularly true when a group of professionals were responsible for a relatively small number of children with invasive devices. There were also concerns that a number of device-related infections arose from skin organisms which found their way into the device when it was used. As more people were involved in a child's care, the pool of possible organisms increased.(P17, P19)

"I am sending in so many different nurses, with all different flora, all different colonised bugs themselves, and then some families have got their own flora, hospital has got another whole shebang." (P17)

In one community organisation, only two nurses were responsible for looking after children with central lines. Because they used their skills frequently, these two professionals became highly skilled in delivering this care. They were able to maintain their skills through regular use.(P19)

"There is only two of us who will do that, so therefore we are not spreading you know we are not spreading the skill amongst a lot of people. There are two of us who are highly skilled at it, that helps." (P19)

Some professionals encouraged families to take on more responsibility for a device to reduce the number of people accessing the device. For example, if a child's parents were able to take bloods and flush saline through a central line, this would minimise the amount of contact that with external organisms. Some professionals felt that families would be more stringent with IPC practices than professionals, and thus would encourage them to be trained in line care.(P19) As I describe earlier in this thesis, some families concurred with this view. Recognising the families' expertise in central-line care was a way for professionals to support good IPC – an example of how coproduction could be used improve health outcomes.(188)

6.1.4 Device removal at the end of treatment

Even within the clinical team, professionals faced challenges balancing the priorities of IPC against other clinical demands. I use the example of device removal at the end of treatment to explore this further. As a general principle, professionals tried to remove

devices as soon as possible once need for it expired (e.g. if a course of treatment had come to an end). However, removing an invasive device was not straightforward, requiring the child to have an operation under general anaesthetic. Some clinicians did not always view the removal of a device with urgency, leading to delays of weeks and sometimes months before the device was removed.

“We can have children that have been off treatment for months before they even get an appointment to have their line taken out.” (P6)

Thus children could be left for months with an invasive device which posed an infection risk and which both families and professionals agreed should be removed. Families were additionally inconvenienced as they needed to have the line accessed and flushed regularly, thus interfering with their lives.(P6, P 17) As I describe earlier in this thesis and explore further in section 6.3.2, these burdens took place away from the clinical setting and were often unrecognised by professionals. Some doctors were concerned that the longer a device was left in place, the more risk there was of infection taking hold.(P3, P17)

“I think we absolutely need to keep their indwell duration to the minimum possible.” (P3)

Not all professionals agreed with this view: for some, the benefits of leaving the device in place in case it was still needed out-weighed the risks of infection. A community nurse who worked with children with cancer explained her reservations about removing central lines quickly. Children who had completed a course of treatment for cancer were monitored carefully throughout treatment and in the months following to check for signs of recurrence. Some children would relapse and thus need a central line for further treatment. If the central line had already been removed, then the child would have to face yet another operation to have it re-inserted.(P17)

“If they have a high risk of relapse, does it really hurt to leave that port in and flush it once a month just to be on the safe side?” (P 17)

For this nurse, her prioritisation of device removal was influenced both by the impact on the child's life and the disease process which made relapse more or less likely. Rather

than adhering to strict timetables, this nurse viewed device removal as a procedure which was tailored to the needs of the individual child and family. Even when the device was no longer required, professionals faced difficult decisions to balance the risk of infection against the child's other needs, again demonstrating the salience of trade-offs.

6.2 The impact of device-related infection on professionals

Caring for a child with a device-related infection was not an uncommon experience for professionals. Sixteen of the professionals interviewed for this study had experience of caring for a child with a device-related infection. The four professionals who had not cared for a child with a device-related infection were all based in the community: two were clinicians who cared for one child with a Portacath (P4, P5), and two were non-clinical (P7, P9).

Confirming the presence of device-related infection was not straightforward and children could be admitted for treatment while test results were awaited. One example of this was with CLABSIs. CLABSIs were confirmed when a blood sample taken from the central line grew bacteria – this process usually took at least 48 hours and children received intravenous antibiotics in hospital throughout this time. Often, the blood sample was negative for CLABSI meaning that children had been treated unnecessarily.(P15)

“I guess not a month goes by when somebody isn't in being treated for a proven or strongly suspected line-infection” (P3)

Although familiar with device-related infection, professionals still found them deeply traumatic events. Children became pale and grey, lost consciousness or had seizures.(P8, P13) One junior doctor explained that children with central line-infections were the sickest children that she had ever looked after. The rapidity with which children became unwell was almost incomprehensible to her, and she struggled to explain to colleagues just how unwell these children became.(P13)

“Until you've seen the first one that sick, you know, go to intensive care or die you don't believe how quickly it can happen or how awful it can be...you know,

you can tell people stories, but you can't communicate it. Until they've, until they've seen someone like until they've seen a child do that" (P13)

Professionals had vivid memories of patients who had developed life-threatening sepsis and feared that children would die as a result of the infection.(P8, P10, P13, P14, P15) One healthcare-assistant explained that every time a child developed a serious infection, she was reminded of other children who had died as a result of the infection.(P10) Even if they had no personal experience of caring for children who had died, professionals were aware of the experiences of their colleagues who had cared for these children.(P13, P14) These experiences influenced how professionals viewed device-related infection, emphasising the risks of what remained a relatively uncommon event.

An important part of the professionals' role was to prevent device-related infection. Professionals felt personally responsible when a child in their care developed a device-related infection. The knowledge that a child had developed an infection after care led some of them to question their own practice, trying to find a point at which the infection could have been prevented.(P10,P15,P17,P18) After a child developed a central line-infection, one community nurse described how she replayed each step of the care she had provided, striving to find a reason for the infection.(P17)

"You always question yourself, exactly as I am sure the parents would." (P17)

Even when professionals were confident that they had not been responsible for introducing the infection into the device, some still felt accountable. One community nurse explained that with each patient who developed an infection, he felt that he should have done more to support the family or provide education. He felt that he had failed the child, and the family.(P11)

"You do feel that you've failed them." (P11)

The feeling of personal responsibility was exacerbated by the attitude of colleagues in the various teams caring for the child. Despite sharing the care of the child, different teams could be quick to dissociate themselves from any infections, deflecting blame onto their colleagues. One example of this was seen with hospital and community teams. A community nurse (P11) explained that he cared for patients who were under

the shared care of the hospital and the community teams. This ethos of shared care was not apparent when a child had to be admitted for treatment of a central line-infection. When a child developed a device-related infection, the responsibility for this was placed on the community team and the child referred to by hospital colleagues as:

*“Another one of **your** community patients.” (P11)*

These feelings of accountability extended to professionals in their management of suspected device-related infection. It was not always clear to professionals whether the infection was a serious one or not, and in some cases treatment could be delayed for several days until tests confirmed the infection. One example was in device-site infections: discharge and redness from a device-site was a concerning sign, but did not always signify that there was an infection present. The presence of an infection around the site was confirmed by taking a swab of the area and waiting for organisms to grow. This process could take several days, and professionals had to decide between starting antibiotics unnecessarily or potentially missing an infection. One junior doctor explained that she felt guilty if antibiotics were not started and the child became unwell while awaiting the results.(P14)

“If they have a temperature it makes you feel quite guilty, it makes you feel like I missed it... what if the child becomes really unwell and I sat on it?” (P14)

The guilt she felt was influenced by the knowledge that the child could develop a life-threatening sepsis as a result of her decision.

Professionals had to make other difficult decisions about the child's care when they developed a serious device-related infection. Decisions about infected central lines were particularly challenging. One way of clearing the infection was by removing the infected line and replacing it with a new one. Children needed the central line to receive life-saving medications or nutrition, therefore it was important that the child had a new line inserted quickly.(P13) However, professionals were concerned the new central line would become infected with the same organism: allowing an interval of days or weeks between removing an infected central line and replacing it with a clean one provided an opportunity to give antibiotics and clear the infection.(P3) The decision to remove an infected device was very challenging for professionals, involving multiple trade-offs.

“It would be that balance between preserving that bit of plastic... but at the same time this could kill the child” (P14)

The decision-making process was further complicated by the relationship between the different teams involved in caring for the child. Not all healthcare professionals appreciated the severity of device-related infections, which made managing infections challenging. One junior doctor working in oncology explained that she struggled to care for children with infected central lines effectively as a result. Using an infected central line could cause a child to deteriorate rapidly, thus a peripheral cannula was inserted. However, nursing staff found it more difficult to give treatment through a cannula, and thus argued for the use of the central line even though this could lead to the child becoming more unwell. Device removal was usually an elective procedure. However, in severe infections, children needed to have their device removed as an emergency. The junior doctor described her frustrations as she struggled to explain that device removal was a life-saving measure to other clinicians, such as surgeons and anaesthetists.(P13)

“You have to argue quite hard to stop using an infected line. And then it’s the challenge of getting an anaesthetist and a surgeon and everyone who’s willing to come and pull a line... you’re relying on other specialities to come and appreciate quite what it means when a neutropenic child has line sepsis.”(P13)

Professionals demonstrated different priorities in the care of a seriously ill child, and had to make difficult decisions at a time when they were still emotionally distressed by the child’s illness.

6.3 Professionals’ recognition of the work that families undertake to care for a child with an invasive device

Many professionals were aware of the challenges that families faced in ensuring that IPC practices were carried out in everyday life. This was particularly true of professionals who worked with patients who were not (usually) hospital in-patients (professionals 1, 2, 4, 5, 7, 8, 9, 11, 17, 18, 19, 20). However, professionals’ insights into the burden that device care placed on families was limited and much of the work that families undertook remained unseen and unrecognised. In this section, I explore

professionals' understanding of the work that families performed in the care of the child with an invasive device.

6.3.1 Professionals' expectations of device care are unclear

Professionals expected families to ensure the child's safety by providing everyday device care and responding appropriately to signs of device infection. However, the expectations that professionals had of families were poorly defined. As a result, professionals and families could disagree about how IPC and suspected device-related infections should be managed while maintaining the child's normal life. The different priorities of families and professionals posed a challenge to establishing shared goals in device care – an essential component of coproduction.(184,185)

Families were expected to protect the child by maintaining a clean home environment, but families and professionals sometimes had different expectations of what this meant in practice. Professionals were largely accustomed to working in healthcare environments, thus their expectations of a hygienic setting to provide device care could differ from that provided by the family.(P11)

"I mean their standards might be very different to yours, but they might be very very house proud. You know, and actually for them they might think that they've actually achieved a really good level of cleanliness." (P11)

Some families became very anxious about hygiene once their child had come home, and professionals felt that they were going beyond what was required.(P10)

"I think once they've gone home, they're still quite anxious about looking after it, some hyper anxious, and actually their procedures far outweigh what we would actually recommend." (P10)

Judging whether a child had a device-related infection or not was important to ensure that the child received adequate care. Families were expected by professionals to recognise the signs of device-related infection in their child, and to respond appropriately by managing the infection or seeking medical help.(P2, P10) Families had to balance the risk to the child from a possible infection against the disruption of yet

another trip to hospital. Getting the balance wrong laid families open to criticism from some professionals: parents who did not bring their child to hospital quickly were felt to be too confident, while those who sought help frequently were deemed anxious.(P12)

“They think they can manage things at home... then you’ve got the frequent fliers that are in and out all the time and perhaps it’s an anxiety issue, that they’re not coping so well at home.”(P12)

Professionals, like the families in this study, struggled to balance the competing priorities of keeping the child safe from infection while also maintaining a normal life.(162,244)

6.3.2 The work that families carry out is not recognised by some professionals

As I describe in Chapters 4 and 5, families were responsible for day-to-day device care and maintenance. Without the care that families provided, children could not safely live at home with the device. However, not all professionals recognised the extent of the work that families undertook when caring for a child with an invasive device at home. As a result, these professionals struggled to appreciate the challenges faced in maintaining device sterility outside of the hospital environment. One junior doctor explained that she had not previously considered how much having a device affected a child’s life at home, nor how the family coped with caring for the child. She was unaware of the difficulties that families faced in everyday life, and later on in the interview exclaimed “...can’t see why families wouldn’t look after it [central line]!”(P13), as though the issue was one of simple motivation.

Nor did some professionals realise the impact that providing ongoing device care had on families’ normal lives. Rather than disruptive events, some professionals viewed invasive devices as a normal part of treatment. As such, the device was not considered to have a significant impact on the child and family. Professionals did not always recognise the effect that ongoing device care had on families’ daily lives.(244) One hospital consultant explained that he saw invasive devices as a routine part of healthcare in his field (Oncology), without which care could not be effectively delivered. As devices were so common in his field of work, he did not regard them as extraordinary

parts of care. Because the use of devices was so common, a network of specialist community nurses provided care for children with invasive devices. As a result, this consultant had less and less input into device care. He felt reassured by his lack of involvement, believing that this was an indication that families managed well with the device, and did not need additional support.(P16)

“I have got no reason to believe that that system hasn’t worked and hasn’t delivered for families... you asked me how do the families cope, the reality is that I don’t round asking.” (P16)

Members of the clinical team developed expertise in specific roles, including supporting families with device care. The demarcation of roles within clinical teams meant that some professionals cared for children with invasive devices without having a clear understanding of the work that families undertook to care for the child. There was little need for them to understand the roles of families as other team members took responsibility for supporting the child and family with device care.(P3, P6, P15, P16) One consultant explained that he felt his role was around the initial device insertion, but not in the ongoing care of the device.(P15)

“Once they’re in [the line], I don’t have too much to do with their day-to-day management, mostly handled by the nursing staff.” (P15)

Another hospital consultant explained that he worked as part of a team with specialist nurses who provided support to families. The work of caring for the child was organised in such a way that he had little input into the everyday requirements of device care, which was seen as the responsibility of the community nurses. As a result, he was unaware of the day-to-day challenges of device care in the home.(P3)

“That is my delegating and admitting ignorance to what we are doing” (P3)

Some professionals felt that there was a clear division between the care provided in hospital, and the care provided in the community. One hospital nurse explained that she felt that care of the device in the family home was the responsibility of the community nursing team and not the hospital staff.(P12) For other professionals, the division

between hospital and community teams meant that they did not consider think about how families managed device care at home.(P6)

“Once they leave the hospital environment, I just assume they won’t touch it [central line]... I don’t know. I never really thought about it.” (P6)

Rather than appreciating the skills and knowledge that families used to maintain their normal lives, some professionals remained unaware of the challenges they faced. Families could be so successful at integrating the care of the device into their everyday lives that their work was concealed from professionals, limiting the opportunities for working together to coproduce health.(188)

Device care was seen by some professionals as a way for families to regain control over their lives, as the child was at home rather than in hospital. One community nurse felt that although initially hesitant, most families appreciated being able to care for the device independently.(P19)

“Most families embrace it because it is the re-empowerment of the family... we have stolen their empowerment for a period of time, for whatever reason, and actually given it back to them.”(P19)

Like some of the families in this study, this community nurse recognised the importance of supporting families to care for the device as a means of regaining control over their everyday lives – a key motivator in families’ care for the child.(162)

The work that families did to integrate device care into their daily lives could be dismissed by some professionals, rather than acknowledged. One nurse working on a day-care unit believed that families found it too easy to carry on with their daily lives alongside providing device care. As a result, she felt that the child was put at risk of infection.(P1)

“They [families] just make it a part of their lifestyle and actually that line then comes into contact with lots of things that you don’t necessarily want it to.” (P1)

Rather than acknowledging the work that families performed and the challenges they faced, some professionals simply did not perceive that this work existed. The work of normalisation (108,244) that families carried out was largely unrecognised.

6.3.3 Recognising the technical expertise of families

As I have described earlier in this thesis (Chapters 4 and 5), families provided much of the technical device care of a child living at home. Professionals recognised that parents were highly motivated to provide safe device care for their child, and relied on their technical expertise to provide safe device care. (P1, P10, P16)

“I think our parents do take very good care of the lines.” (P1)

Parents’ role in device care was influenced by the availability of services in their local area. Some families lived in sparsely populated areas. As a result, community nursing services were unable to provide routine care to maintain the device, such as flushing a central line or changing a gastrostomy button. Accessing these services in a specialist centre meant travelling long distances, causing significant disruption to the family. In such areas, families were encouraged to take on these cares themselves.(P19)

“Often our philosophy is to encourage as much as possible to care for their own devices.”(P19)

Professionals were motivated by a desire to minimise the impact on the child’s normal life, and by the gaps in service provision in the area. By supporting families to care for the device themselves, the goals of providing safe care for the child and minimising disruption to family life could be achieved – although additional burdens were placed on the family as a result.

Some professionals acknowledged the work that families did in caring for the child and the expertise that they developed when providing this care. Recognising the work that families did was important for their confidence in caring for the child. One community nurse explained that by emphasising the confidence that he had in families and the work that they did in caring for their child, families were more receptive to suggestions for improvement.(P11)

“Accentuating the positives, and actually saying this [advice] is going to help you... and give them that confidence as they walk through the door.” (P11)

Other professionals found the expertise of families challenging. As I describe in sections 6.1 and 6.2, professionals felt that their role was to prevent device-related infections and to treat infections if they did occur – families’ expertise in device care could threaten this role.(183,266) One junior doctor had experience of one mother who had undertaken all central line care for her child, including taking bloods and administering medications. As a result, the child was discharged home on antibiotics which would normally have kept her in hospital. The child was no longer under the observation of the medical team, but the junior doctor felt that she was still responsible for the child’s safety.(P14)

“You’ve kind of lost control of the situation because that’s a medical device that the child’s got it, and you kind of want ownership of it...the ultimate responsibility is yours.” (P14)

This professional described this challenge as a form of role strain. Although professionals wanted to support children to live a normal life and minimise their time at home, there was sometimes a conflict with their professional responsibilities to treat infection – a form of role strain which families also experienced.(267)

6.3.4 Recognising the burden of role strain on families

Families in this study (section 5.5.1) described the challenges of balancing their roles of parenting with the demands of providing device care – a phenomenon known as role strain.(267) Notwithstanding the significant emotional, cognitive and technical labour that families described in Chapters 4 and 5, professionals displayed only a partial insight into the extent of these burdens and their impact on families.

Some professionals recognised that trying to balance the roles of both parent and carer was challenging for families.(P2, P3, P11, P16, P17)

“Coming to terms with that is quite challenging for patients and families because they [parents] now become their carer.”(P2)

Some devices, such as tracheostomies and gastrostomies, required frequent intervention, thus professionals felt that families had little choice but to take on the role as carer.(P12, P19) Other devices, such as central lines and Portacaths were not used as frequently, and therefore the parents did not have to provide regular care for the device.

Nonetheless, professionals felt that parents had to remain vigilant at all times to ensure that the child remained safe and that any complications were addressed promptly.(P1)

“They [parent] have to take responsibility for the safety of the line because you can’t have someone there 24/7.” (P1)

A specialist nurse had experience of supporting families in the community. Supporting families to do to access and take bloods from central lines meant that there was greater flexibility around travelling, and the family could go on holiday without having community nurse input. Some professionals reported that some parents found the experience of using the central line very difficult and did not want to carry out this care again.(P1)

“They have gone on holiday and they have needed to do something and they have come back and said – no, that scared the hell out of me. I am not doing that again.”(P1)

These experiences meant that the nurse was concerned that parents were trying to take more responsibility for the device than they were ready for. She recognised that parents were motivated by different reasons to take on more responsibility for device, and was concerned that external pressures would force some parents to agree to provide care that they did feel ready to do.

“It is difficult to offer it [training to use a central line] at the moment because we don’t want people to say yes because they think that they should make our workload less.” (P1)

When professionals recognised the impact that role strain had on parents, it could make some less willing to support families to take on additional device care.

Not all professionals recognised the strain that being a parent-carer put on families. One nurse (P12) explained that caring for the device was an essential part of the child being discharged home from hospital: she felt that parents were accepting of their new role as it meant their child could come home.

“The parents have coped very well with it because it is a treatment that’s going to enable them to get home.” (P12)

6.3.5 Recognising the impact that device-related infection has on families

The families in this study described device-related infection as worrying and traumatic events (section 5.2). Some professionals recognised the anxiety that parents felt around device-related infection, and the additional burden that this fear imposed on families.(P2,P12,P19) They recognised that the potential consequences of a device-related infection – hospital admissions, additional surgery, loss of work – were an additional burden for families to carry in addition to the daily work of device care.(P3, P6,P16) However, the fear of infection was only part of the burden that families had to shoulder. As one nurse explained, the fear associated with device-related infection competed the with other anxieties that families felt regarding their child’s health, thus infection was not always their primary concern.(P20) IPC measures were merely one part of caring for the child who had a number of other needs. Some professionals expressed concern that families did not share their goals of maintaining IPC, particularly when there were competing pressures..(P12)

“When you’ve got so much to do for, potentially for that child anyway, you might think oh, well I won’t, I won’t clean that trachy this morning, I’ll do it tonight.” (P12)

Fear of device-related infection was viewed positively by some professionals who felt that families were more vigilant as a result.(P2) Conversely, families who were not fearful of device-related infections were felt by one nurse to be too complacent, which delayed them from seeking medical attention.(P12) Fear of infection could be a means of encouraging families to be more scrupulous about device care.(P2) However, professionals had to tread a fine line between using fear to persuade families to comply

with device care, and adding too much to their emotional burden. One example was when families were advised to keep the central line dry during bathing. Nurses realised that the emphasis that was placed on this infection prevention measure could lead to a great deal of anxiety for children and their families.(P1, P2, P10, P20) Professionals tried to find a balance between emphasising the importance of IPC while avoiding needless anxiety for families.

“tape it [central line] round when they’re having a shower, to keep it as dry as possible, but not to freak out if it’s slightly a bit wet” (P10)

As one day-care nurse (P2) explained, some families could become so fearful of infection that their emotional wellbeing suffered. Awareness of the emotional burden that the fear of infection placed on families helped professionals to tailor their advice in a way that supported the family without causing them additional distress – another example of the trade-offs that professionals engaged in.

“I suppose it is trying to minimize it to the point where they are not anxious to the point of really getting sort of upset and not being able to cope with it.” (P2)

Other professionals did not fully appreciate the extent of the emotional burden that a device-related infection had on parents, nor did they recognise the trade-offs in which parents routinely engaged:

“They [parents] are surprisingly oblivious... I guess it is low on their list of thoughts this is going to be a line-infection even though you remind them frequently.” (P18)

“I always sense a bit of complacency [about device-related infection].” (P14)

Although professionals recognised the importance of a normal life for children and families, this was not always the priority when faced with a potential infection. One professional expressed concern that the disruption that families envisaged as a result of a suspected device-related infection meant that some families delayed presenting to hospital.(P12)

“Some families are very reluctant to come in to hospital so that’s quite distressing, because they’ve probably had numerous hospital visits, so they don’t want to be in hospital. So sometimes they can keep their children at home for a bit longer than perhaps they ought to, because they think they can manage things at home because they don’t want to come in to hospital.” (P12)

Device-site infections were viewed differently from central-line infections by professionals.(P3, P7, P18) Some professionals recognised that device-site infections were painful for children, and that managing these infections could be challenging.(P3, P12) Others seemed unaware of the impact that a gastrostomy or tracheostomy site infection had on the quality of life of the child and their family.(P7, P18)

“It is not a massive upheaval for them... but it is just more of an ongoing nuisance really... so I don’t think a lot of the time it is a massive burden.” (P18)

The way in which device-site infections were experienced by families contrasted with the perception of their impact by professionals. As I describe in section 5.2.1, families experienced device-site infections as significant, painful, and disruptive events. Despite the substantial consequences of device-site infection on children and families, these effects remained largely unseen by professionals who did not, in the main, appreciate their impact on children’s normal lives.(244)

6.3.6 Respecting the decisions that families make

As I describe in chapter 4, families were engaged in complex trade-offs to try and maintain device care while supporting the child to live as normal a life as possible. Some professionals shared this goal with families – although their understanding of what a “normal” life meant varied. One consultant explained that his aim for this patients was for them to experience as few limitations as possible. He encouraged children to take part in physical activities and trips so that they could do the same as their peers.(P15)

“I want them to go to school, I want them to go to the cinema, want them to do stuff, whatever they feel up to doing.” (P15)

However, many professionals felt that the risk of device-related infection was an inevitable consequence of pursuing a normal life. By taking part in everyday activities, such as going to school, children were exposed to potential infection.

“Normal life is the infection risk.” (P8)

Some professionals felt that families placed too much emphasis on normal life, rather than making the care of the device their priority.(P1, P12) The sophistication of the decisions that families made to balance device care with normal family life was not always understood by professionals. One nurse explained that families sometimes went against the recommendations of the clinical team. She seemed unaware of the difficult decisions that families constantly made to provide the best care for their child.(P12)

“And some of them are given advice by professionals, but then choose not to accept that and just do their own thing anyway.” (P12)

Professionals displayed mixed feelings about the importance of device care relative to the importance of a normal life. One day care nurse (P1) initially expressed concerns that families placed too much emphasis on pursuing a normal life for their child, rather than making device care their priority. However, later on in the interview, the same nurse also worried about the impact that strict adherence to IPC guidelines had on the family. She felt that some device-related infections could have been preventable, but only if the parents had placed strict restrictions on the child’s activities. Such restrictions could in themselves have a negative impact on the child’s wellbeing.

“That is something that the parent could have prevented but then do you want to say that you can’t do any of the things... you could let it rule your life trying to be careful with it.”(P1)

Professionals’ perceptions of the decisions that families made about device care were influenced by the desire to keep the device free from infection as well as allowing the child to take part in everyday activities. Some professionals felt that their role was to support families to manage the risk of infection rather than imposing stringent guidelines that families would find unworkable. They recognised that families were unique and that they had different priorities in the care of the device. Therefore, strict

adherence to all aspects of IPC was not the priority for all families.(P2,P3,P10,P11,P16,P17) Families and professionals were able to work together to respond to these different priorities.(183) By responding to individual families' needs, professionals reflected the way in which families provided care in their own homes.(189) Families in this study explained that they interpreted the information they were given to provide device care in a way that maintained normal family life as much as possible. One community nurse (P17) recognised families' needs were different and tried to tailor the advice she gave to support this goal of normalisation. Rather than providing the same guidance to every family, she based her advice on her knowledge of that particular child and their environment.

"It is very difficult to give consistent advice because all of the children are different."(P17)

She recognised that carrying out IPC was made more difficult if IPC recommendations were not practicable for a particular family. This nurse made pragmatic adjustments to the advice she gave which made it more achievable for families to comply with.(P17)

"How many families have got a shower big enough to get them and a child in, and a lot of families haven't got showers they have only got showers over the bath [...] I would find a way round it so they could have a bath." (P17)

Professionals also tried to support IPC practices while minimising the disruption to the child's emotional wellbeing – a further example of normalisation while maintaining device safety. One example that professionals gave was of close contact between children and pets. While conceding that this could pose an infection risk (particularly if the pet chewed or licked a device), professionals also appreciated the important role that pets played in children's lives. They supported families to find a balance between maintaining cleanliness and living their lives as normal.(P2, P10, P13)

"If they have always had a dog you are not about to say you have got to get rid of your dog but obviously taking more steps and being more hygienic around the dog and washing your hands and that sort of thing." (P2)

A similar dilemma arose when children had favourite toys or comfort blankets. One community nurse described one of his patients who had a favourite toy which was on hand at all times, including when the central line was being used. He was concerned that the toy would harbour bacteria and that this posed a possible infection risk to the child.(P11)

“[toy] went to her bottom when she was itchy, and [toy] would help scratch her bottom, and then [toy] would then help her hold the line.” (P11)

However, he also recognised that the toy was important to the child, particularly when she was ill. If the toy was removed when the central line was being used, the child became very distressed and uncooperative. The family had to decide between causing acute distress to the child by removing the toy, or continue with a potential risk of infection in the future. Eventually a solution was reached by the parents washing the toy overnight when the child was asleep. By working with the family, this nurse had succeeded in minimising one infection risk while causing the least disruption to the child.(P11)

The trade-offs that needed to be made meant that some professionals felt that it would not be possible to adhere completely to all infection control guidelines, and some device-related infections were inevitable. When asked if central line-infections in the community were preventable, one specialist nurse replied:

“I don’t think so because of the individuality of people and their lifestyle and the way they live.” (P2)

In the end, supporting families to live a normal life meant that the child would be at risk of infection.

6.3.7 Working in teams with different professionals

The expectations of different professionals could also differ. The numerous different clinical teams involved in children’s care meant that establishing IPC practices was not straightforward. Policies around device care varied between different teams, which caused confusion for families and professionals alike.(P11) Some areas of good practice

existed where hospital and community teams had shared guidelines for central line care.(P1, P18)

“We have strict policies that everyone follows and the community equally follow the same policy.”(P1)

The different clinical teams who cared for the child with an invasive device had different levels of experience in device care. Some professionals worked in specialist services which cared for a large number of children with invasive devices. When the child lived some distance away from the specialist service, the care of the child was shared with other teams who were less experienced in device care. The distribution of responsibility between these teams posed challenges when working together to care for a child with an invasive device. Some professionals struggled to have their expertise recognised by colleagues – an experience shared by families in this study.

A GP outlined the challenges in supporting a child with a Portacath in a remote part of the country. The location meant that the GP practice would be directly responsible for the child with the device, without rapid access to the tertiary centre. The family, tertiary services, and local clinicians all felt that inserting the device was necessary for the child’s care. Although the practice team had thought carefully about the training and facilities that they would need to be able to support the family, the tertiary service who oversaw the child’s care remained unsure about the local team’s ability to care for the child.(P4)

“One of the hardest things actually is persuading tertiary centres to trust us to take on things that they are used to doing.” (P4)

The lack of confidence in the local team from the tertiary centre meant that the child’s care was disrupted, and it was uncertain if she could have the Portacath inserted. In the end, a trainer from the tertiary service took time from his family holiday to train the local team:

“He [specialist nurse] took a week’s leave and brought the family over and had a week’s holiday but supported us in learning how to manage the Portacath at the same time.” (P4)

Even within established clinical networks clinicians were not always confident that their colleagues' practice was of an acceptable standard. One nurse described how she had concerns when a child had recurrent line-infections and had been cared for by an inexperienced member of staff. In order to assure herself that the care provided was up to standard, she carried out a joint visit with the other nurse to oversee her care.(P17)

"I will go and try and do a sneaky double up visit, just to make sure I think their practice is how it should be." (P17)

Problems with trust between clinical teams also arose when a child developed a device-related infection. Children who lived at a distance from their tertiary centre often presented to their local hospital with suspected infections. The local hospitals were responsible for identifying a possible device-related infection, and starting treatment quickly. Children with central lines who were receiving treatment for cancer were at risk of severe infection, thus national guidance stated antibiotics should be given immediately.(268) One doctor at a tertiary service did not feel confident that the local hospital were able to carry out this care adequately. She felt that the local hospital were unaccustomed to dealing with children with immune deficiency, and therefore the clinical staff did not always appreciate the urgency with which these children needed to be treated.(P13)

"If they're in a shared care centre that don't see many kids with febrile neutropaenia there's a real worry that staff there won't appreciate what they're dealing with." (P13)

Junior doctors explained that these concerns could be perceived by families. Families knew that they were advised to seek urgent medical help if their child had a suspected CLABSI. Some parents would rather drive for two hours with an unwell child to reach the specialist hospital rather than attend their local hospital with whom they had little relationship and where they did not feel that they would receive adequate care.(P13, P14)

"They'd learned through time how to gauge when they need to go to their local hospital, and when they're not going to get adequate advice, so they just come to us [specialist hospital]." (P14)

The relationship between professionals affected the help that families sought when dealing with suspected infection.

6.4 Influences on partnership working

Notwithstanding the challenges I describe in section 6.3, both families and professionals described examples of where they worked in partnership to provide optimum care for the child. Professional practices and ways of delivering care could be adapted so that the goals of device care and normal life were met. Relationships developed between families and professionals which further supported the delivery of care.(184)

Ultimately, families and professionals could use their shared expertise to ensure that the child received the care best suited to their needs.

6.4.1 Developing services to support children in the home

The development of specialist services meant that many children could maintain life at home while still receiving appropriate device care from professionals. Families particularly valued the role of community nurses who supported children at home. By visiting children in the community, the everyday life of children could be preserved.

“They are really, really crucial in keeping things normal because otherwise the kids have to go into hospital.” (P8)

One father explained that his daughter had just started school. Community nurses visited her during the school day to take blood from her central line. Without this service, his daughter would have had to take time away from school to go to the hospital. The support of the community nurses meant that the girl could continue to attend school, and the time spent away from her classmates was minimised.(F7)

“The nurse would go to the school so that she didn’t miss class.” (F7)

Nurses developed skills in carrying out device care in ways that adapted to the child’s life. Rather than expecting the child to come out of their classrooms or playtime, some community nurses carried out device care during lessons. One community nurse explained how he could use a central line in the middle of a classroom of young

children. Part of his expertise was to ensure that device care was carried out safely in an environment that was not designed for that purpose.(P19)

“I have done it [used a central line] in the middle of a classroom, with about 20 little five year olds standing around me once or twice.” (P19)

This skill enabled children to return to school and live a normal life at the same time as maintaining the safety of the device.

The support offered from community nurses was particularly valued as the advice was tailored to the family outside of the hospital. Some families felt that community nurses had a better understanding of home life with a device compared to hospital-based healthcare professionals.(M6, M8)

“The nurses on the ward are great... but they don’t have to deal with the day to day life bit.” (M8)

One mother described how her community nurse had supported her to care for her son with a tracheostomy while he was still an inpatient. Although the mother had received training in tracheostomy care from the hospital staff, she was very unsure about how she would manage at home. The community nurse supported the mother to spend time away from the hospital with the child, and provided education on tracheostomy care away from the hospital environment. During the time away from the hospital, the nurse would rehearse different emergency scenarios with the mother, so that she was prepared for these eventualities once at home. The support from the community nurse continued once the child was discharged home, supporting the move from hospital to home care.(M6)

“It was a good experiment really, and showing us what to do, and she came and visited us at home, to check we were alright.” (M6)

This example demonstrates how community nurses supported families during the transition from delivering device care in the supported environment of the hospital, to becoming independent carers in their own home.

Community nurses worked across teams to share information about the child's care. One child was in a school for children with special needs which had nursing staff on-site. The nurses in school worked closely with the specialist community nursing team, and staff often worked across both teams. There was good communication between the family, and the nursing teams in school and at home. The nurses became familiar with the child's gastrostomy site, and its normal appearance. As a result, nurses in school and at home could recognise changes to the gastrostomy that could indicate infection, and intervene early to manage this.(M16)

"We've got nurses on site at school... they're linked to the acute nursing team as well, in fact there's crossover of nurse. So that works really, really well." (M16)

By working together, families felt that support from good community and specialist nursing teams home led to fewer hospital admissions for device-related complications, including infection. Device-site infections were managed at home with the support of community nurses, rather than needing visits to the hospital.(M14, M16, M17)

"Without that team I think...constant back and forth to the hospital for infections and advice" (M16)

The development of a specialist service of professionals to support children at home was invaluable to allow children to have a normal life while maintaining the device safely.

6.4.2 Relationship between families and professionals provides support for both

Families interacted with a wide range of different professionals. It was important for families that they could build a relationship with the professionals involved in their child's care. Some families (F4, F5, M6, F7) explained that when such relationships developed, they felt confident approaching professionals for support and advice, working together towards shared goals. Where families had the opportunity to build a relationship with the community team over time, both parents and children felt more comfortable with that member of the team. Children knew what to expect from the nurses when they knew them well.(F4, F5)

“He just gets to know [Name 1] a bit and [Name 2] and he gets to know them so he knows what to expect.” (F4)

Even when children built relationships with a number of different team members, they still expressed a preference for a particular nurse to carry out device care.(F5)

The relationship allowed the families and professionals to share information with each other that could otherwise have been challenging. One community nurse explained that he found it difficult to address topics such as hygiene and cleanliness early on in his work with a family. As time went on, and a relationship developed, IPC issues were easier to address. Relationship building was the foundation for ensuring that infection control was maintained.(P11)

“I’ve got to have this conversation fairly quickly, but I need to develop a relationship with this family, I need them to trust me.” (P11)

The relationship could provide emotional support for both families and professionals. Families could also provide reassurance to professionals whom they knew well. One father described how the same community nurse visited their family every month to provide Portacath care for this two sons. The elder son developed an infection around the site of his Portacath which led to the device being removed. The community nurse was unaware of what had happened until the monthly visit, when the family had to explain to the nurse. The nurse was visibly upset and expressed concern that the family no longer had confidence in the care he provided. The family were able to reassure the nurse that they had confidence in the care provided. (F4)

“We were like ‘look what can you do, we see you clean it, we see you wash your hands, we see you put gloves on, what can you do, you know, it’s one of those things, you’re doing it in a house, it’s a non-sterile environment, it’s one of those things, what can you do’, so that’s that really, there’s no point, kind of, saying he did anything wrong or whatever.” (F4)

Establishing trust between families and professionals was a gradual process which took place over months and years.(P14) One family reported that rather than build a close

relationship with one or two nurses, they had had to interact with whoever was available.

“You don’t know any of them. Whoever is available, you don’t get the same one.” (M1)

Failure to build these relationships meant that professionals remained unaware of family concerns. A healthcare assistant in a hospital explained that in her experience, no families had raised queries about device care either in hospital or at home.(P10)

“I’ve never heard any parents query the care of the line by the nurses.” (P10)

There was a discrepancy between the experiences of families and the perception of professionals who provide device care. Despite the difficulties that families described, some professionals seemed unaware that families had concerns about their child’s care. This finding mirrors work in patient safety where families struggle to raise concerns with professionals.(139,269) The lack of trust impacted on the care of the child. As one specialist nurse explained, it was important that the trust was mutual – not just one way. The close relationship between families and professionals was essential for the care of the child at home:

“We don’t have these patients for like five minutes... they build up a rapport with you and they can trust you and you can trust them. I don’t think it would work any other way.” (P2)

When there was close working between families and professionals, both parties received both technical and emotional support in challenging circumstances.

6.4.3 Families negotiate care where professional advice is inconsistent

Some families struggled to build relationships with professional teams especially when the advice they received was contradictory or seemed inconsistent. One family had been advised by the specialist nurse that the ends of the central line catheters (“bungs”) needed to be changed on a weekly basis. However, this was not carried out by the community nursing team who were adamant that this was not necessary.(M1)

"I can't tell you the last time they were changed. [specialist nurse] says that is a cause of infection whereas the nurses are saying they don't need to be done as often." (M1)

This family felt that the nurses involved in their care did not fully understand the issues that their child faced and lacked the expertise to support them. As a result, the family avoided contacting the community nursing team and instead went straight to the hospital or the oncology speciality nurse.

"We can't ask specific questions because they don't know the answers. I think my mum asked them a question once at pre-school but that was a mistake because they gave her an answer that wasn't necessarily...not to act upon but it wasn't right."(F1)

This is one example where inconsistent advice led to a lack of trust between family and professionals. The family used their expert knowledge of the health system to change the way they sought support for the care of their child.

Families and professionals were aware that inconsistent advice could lead to a breakdown of trust. Different groups of professionals undertook device care differently, and had different protocols for care.(P11) The reasons for this were not made clear to parents, and the inconsistencies could cause confusion and distress.(F1, M6, M11) As a result, families had to evaluate the information they were given and evaluate this in the context of their own experiences.

"I think you've got to take what they [professionals] say and think how can I fit that into how I work?" (M6)

One example of this was when washing hands before carrying out device care. Families were sometimes more fastidious than professionals in ensuring that hands were washed before device care took place.(P15) One community nurse explained that she usually used hand gel rather than washing her hands before carrying out device care. Her experience was that some homes did not have adequate facilities to ensure that she could wash her hands to the required standard, or then dry them on a clean towel. Hand

gel that she carried herself was seen as a more reliable method of cleaning the hands, and did not rely on families providing equipment that met the standard that professionals required.(P19)

“The rationale for that is quite often you are washing your hand in the sink with some dodgy soap you don’t know what it is, and at the end of it the carer turns, the parent turns round and gives you a tea towel or towel to dry your hands on and you think well that was a waste of time.” (P19)

The discrepancy between the care that families provided and the techniques used by professionals could cause tension when care was being delivered in the child’s home. One mother felt that professionals who used hand gel as an alternative to washing their hands were not cleaning their hands adequately.(M19)

“I think a lot of people can become lazy about it, then they just think I don’t need to wash my hands, use hand gel.” (M19)

There were also discrepancies in the way that parents and professionals used gloves when providing device care. Both parents and professionals felt that using disposable medical gloves was important to reduce the risk of central line-infections.(M2, M19) There was less agreement when it came to gastrostomy care: some parents felt that gloves were there to protect carers rather than the child, and as such, did not feel that they were important.(M6, M15) Other parents had been actively dissuaded from using gloves for gastrostomy care by professionals.(M6, M9, M15) These discrepancies could add to the tensions between families and professionals. One mother explained that community nurses and care assistants were supposed to wear gloves when caring for her son, even though the mother felt this was unnecessary. However, the gloves were often brought into contact with other surfaces before being used for device care. The mother was concerned that the way in which the gloves were worn and used actually detracted from their use as a clean barrier.(M19)

“Surely that’s not right, because you’re using the gloves that you’ve had shoved in your back pocket of your jeans, so they’re, that’s defeating the object, of the reason for wearing the gloves... And then the other thing that she would do is

she would put the gloves on, and then she'd go around doing lots of things with the gloves on, and then do the procedure.” (M19)

Rather than providing reassurance, this mother felt that using gloves was a way for some care assistants to mask poor hand hygiene in her home. Despite raising her concerns, this mother felt that her contribution was ignored.(139) Failure to respond to her concerns further contributed to the loss of trust between the mother and the professionals who cared for her son.

6.4.4 Families and professionals use their shared expertise to care for the child

Professionals had to find the balance between ensuring that the child received safe care, and respecting the family's autonomy. As the trust between professional and families developed, families were supported to take on more decision-making roles. Community teams provided families with more support and reassurance early on in the journey, becoming less involved as time went on.(M20) One community nurse felt that trust in the family was an important part of their taking responsibility for the device, and learning to provide care. His role was to support the family developing that autonomy, but not to over-ride the family's decisions unless there were serious concerns about the child's safety.

“When you're a community children's nurse, they [family] are actually in charge, but it's a partnership still really...If you want them [family] to take responsibility then you need to show that you can trust them.” (P11)

Some professionals supported the development of parental expertise by consciously providing more support in the first few weeks and months at home. One nurse explained that although the parents were advised to call the unit if they had any concerns about a child with a central line, some families were reluctant to disturb the staff. The nurse addressed this by reinforcing the message that parents should call if they were concerned, and supplemented this advice by calling the parents herself.(P2)

“We have had a newly diagnosed patient and just out of courtesy to make sure the parents are okay we give calls once a week.” (P2)

By working together, professionals could support families in maintaining a safe environment.(P2, P11, P15) One nurse gave an example of working with children with cancer who had periods of low immunity associated with their chemotherapy treatment. This was monitored through regular blood tests. Sharing the information about their child's immune status with families meant that they were aware of when the child was at greatest risk of developing infections, and could make informed decisions.

"If parents can keep really up to date with blood results so that they know when the count is low so reducing those risks." (P2)

In this way, families were given information and supported to make decisions that were safe for their child.

Some professionals recognised that families developed expertise that they did not themselves possess, and were happy to learn from them. Most families had relatively little contact with their general practitioner in relation to the invasive device, relying instead on hospital or community specialist nursing teams. Some families felt that the GP had little experience of dealing with children with invasive devices, thus the support and advice that they could offer was limited.(F4, M6, M14) In some cases, the GPs' lack of experience gave parents more control over the child's health, as clinicians deferred to the parent's expertise.(M16, M18)

"The doctors tend to say we don't know, tell us what you think, whatever you tell us you think he needs that's fine." (M16)

In one remote area of the country, the mother of a child was trained to use a Portacath, but not all the staff at the GP practice were. When the mother and child attended the practice to flush and use the Portacath, the mother could demonstrate how the device was used to healthcare professionals.(P4, P5)

"Because Mum does the flushing when she comes in with the child she is able to tell the doctor on duty, if the doctor on duty is not that familiar, she can talk the doctor on duty through it now." (P4)

Families could assist professionals in making clinical decisions. One junior doctor explained that healthcare workers tended to recognise signs of infection by clearly defined parameters, such as a rise in temperature. However, she recognised that the parent's evaluation of their child was also an important indicator of illness.(P13)

"They're experts in their child, they do know this is not what my child is normally like." (P13)

The expertise of families was particularly important as children were cared for by a large number of different professionals.(M9, M6) One mother described how a consultant at her local hospital had decided that her son would benefit from having a Portacath inserted. The family had already discussed the possibility of Portacath insertion with a consultant at a specialist hospital. The family and specialist consultant had discussed the child's clinical condition (including immunosuppression and existing devices), and had decided that the risk of infection was too high to justify inserting the device. When the mother explained these concerns, the two consultants discussed the child's care, and the Portacath was not inserted.(M6)

"they were going to put it [Portacath] in [local hospital] they were going to put it in, and, I said could you just check with [specialist hospital], I said please check we've been through something else before, and he said just another site for infection." (M6)

In some cases, treatment was suggested by one clinical team but the implementation was left to another. One mother described how her daughter had a gastrostomy inserted under private health insurance. The site became infected and the private consultant recommended that a topical cream be used. Although the initial prescription was issued from the private hospital, the mother then had to go back to the GP for further prescriptions. The prescription was not one which the GP practice normally issued, and was not regularly used by the local hospital. The mother was able to present the information to her GP and to explain the impact that using the treatment had on her daughter's quality of life, and the cream was continued.(M18) This example demonstrates how parents manage the flow of information between different health professionals to optimise infection control and device care in the home.

Services could adjust their ways of working to recognise the expertise of families. One mother had been advised by the specialist hospital team that she could and should learn to access her son's Portacath at home. When she raised this with her local team, the community nurses were initially reluctant to support this as parents in their area did not usually access central lines. Once the mother was able to demonstrate that she would be able to learn how to use the device, the nursing team offered to provide training and became a source of support to the family at home.(M10)

"The [community nursing] team are very good... They took care of all my training, which they were reluctant to give me because they don't usually train parents." (M10)

This is an example where the community nursing team recognised that the mother had the technical expertise to care for the Portacath, and adapted their service to support her to care for her son.

6.5 Summary

This chapter describes the wide range of different professionals involved in supporting the care of the child in the home, and how these professionals work with children and families to deliver device care.

Like the families in this study, professionals engaged in a series of trade-offs when caring for a child with an invasive device, although their priorities differed from those of families. Rather than making impartial decisions about the care of children with invasive devices, professionals were stakeholders in these decisions who were influenced by their experiences. Most of the professionals had direct experience of caring for numerous children with CLABSI, some of whom had become seriously unwell – some had even died. Caring for the child suffering from a significant CLABSI was a deeply traumatic experience which some found difficult to articulate.

Professionals who cared for the child before they became unwell felt guilty if the child developed an infection, even though they felt their clinical practice had been appropriate. An important part of the professionals' role was to prevent the child from developing a device-related infection, and to ensure that such infections were treated appropriately when suspicion arose. Thus for professionals in this study, device-related

infection was a traumatic event for which they felt responsible. Professionals maintained an uneasy balance between relying on the technical expertise of families to carry out device care safely, and maintaining professional responsibility for the safety of the child.

Professionals described examples of trade-offs in their care of children with invasive devices where IPC was not always prioritised. Minimising pain and distress to the child (e.g. by avoiding Portacath access, or not waking the child when using a central-line) were examples of these trade-offs in professional care. However, not all burdens on children and families were clearly seen by professionals. Professionals recognised that normal life was an important goal for children and families, but they did not fully appreciate the work entailed in pursuing this goal. As I describe in Chapter 5, maintaining IPC in the context of the child's normal life imposed a significant workload on families. This work was largely unseen and poorly recognised by professionals. Where professionals did recognise the work that families undertook, they were not always supportive. Some professionals recognised that normalisation meant families took on additional work – such as accessing central-lines to facilitate a family holiday – and were wary of encouraging families to take on further burdens. Families' work to integrate IPC into their everyday lives was sometimes viewed by professionals as having a disregard for the risks of device-related infection. Some professionals even found the fear of device-related infection a useful mechanism to promote compliance with IPC practices, even while recognising the heavy emotional burden this imposed on families. Thus while professionals and families shared some goals in the care of the child, IPC remained the priority for most professionals.

Despite these challenges, examples of partnership working occurred where families and professionals worked together to maintain IPC while pursuing normality. Professionals gave examples where they prioritised some aspects of the child's life over strict adherence to IPC, for example where there was an emotional benefit to the child. Sharing information with families supported them to make decisions about the relative importance of IPC at different points in the child's journey. Other professionals described how they worked with families to develop strategies which supported both the families' priorities and promoted IPC in the real world environment of the child's home.

However, these partnerships were dependent on close relationships which were established over time. Without these relationships, families' concerns were unheeded and professionals were unable to provide the support needed to maintain device care safely.

In Chapter 7, I discuss the implications of the multiple influences on children, families and professionals when caring for a child with an invasive device at home, and explore how all parties can work together to optimise the care of the child.

7 Discussion

In this thesis, I have explored how children, families, and professionals work together to maintain IPC practices in the care of a child with an invasive device at home. I have drawn on the experiences of children with invasive devices, their families, and the network of professionals who support them to investigate the challenges in maintaining IPC, and how these challenges are met. By using a qualitative research methodology, I explored how children, families and professionals make sense of guidance on IPC in the context of their everyday lives.(197,198) This approach was particularly useful to investigate how families carried out the advice they received, and to examine the complex decision-making processes and factors which influenced these decisions.(192,197,198)

Twenty families were recruited, resulting in semi-structured interviews with eighteen mothers, four fathers, and twelve children. Interviews were also conducted with twenty professionals who worked with children with invasive devices living at home. Analysis of the data from interviews with families and professionals, enriched by field observations in the family home form the results presented in Chapters 3 – 5.

The original aims of the research were to:

- Explore the views of children, families, and professionals as to which factors place children living at home at risk of device-related infection.
- Explore how children, families, and professionals understand and assess infection risks associated with an invasive device
- Examine the actions and strategies that children, families, and professionals use to minimise the risks of device-related infection, and what challenges are faced in implementing these strategies
- Propose how best the efforts of these partners can be coordinated and supported in order to optimise infection control.

As I describe in Chapter 1, device-related infections are a significant problem for patients, families and healthcare services. Attempts to reduce these infections in the

hospital setting have largely been successful, but replicating these successes in the community has proved challenging. Initiatives to reduce device-related infection in the community have focused on training patients and families in the technical care of the device, but have not explored how device care is carried out in the community or why lapses in IPC occur. I suggest that a crucial factor in device care in children in the community is the desire for children to live as normal a life as possible.

Normal life for children is compromised by both the presence of the device, and the IPC practices required to keep the device safe. I have demonstrated that children and families prioritise trying to live a normal life for children with invasive devices at risk of device-related infection. The pursuit of normality is a key goal for parents as they attempt to integrate device care into everyday family life. Families make complex and sophisticated decisions to balance the conflicting demands of device care against the demands of everyday life. Their efforts to manage infection risks, and the trade-offs they are prepared to make, can be understood in the context of this over-riding goal of pursuing normality. Normalisation – where families emphasise and pursue aspects of their lives which are considered parts of normal childhood – is well described in children with chronic illness.(162) I argue that normalisation is a key factor which influences IPC in children with an invasive device; the role of pursuit of normality as a factor which influences IPC has not previously been described in children at risk of device-related infection.

Co-production models recognise that healthcare, including IPC, is achieved through the contributions of different parties – including families, health professionals, and community professionals (183), but this research has shown that families and professionals do not always recognise each other's perspectives or work towards shared goals.(119,183,188) Some professionals in my study appeared to have limited insight into the difficulties that families face. A particular challenge is that the pursuit of normality by families can come into conflict with clinically driven goals of optimal line care and minimisation of infection risk causing tensions in relationships between families and health professionals. Families' priorities are not always respected, and families are not always able to access the knowledge or resources they need to help them achieve their goals. Thus this thesis offers a novel perspective on challenges to the

aspirations of coproduction of IPC in the context of children with invasive devices living in the community.

There were examples of professionals supporting and working in partnership with families to help them achieve the goals of reducing device-related infection alongside a normal life for the child. When professionals and families worked together towards shared goals they were better able to develop solutions which were appropriate for individual families, and which made best use of the expertise of all concerned. This way of working might be considered more in line with the aspirations of co-production – as I explore in more detail in section 6.7.

I begin this chapter by outlining the importance of normality to children and families. I expand on this concept further with specific reference to the challenges to a normal life that maintaining IPC poses (sections 6.2 – 6.4). Maintaining a normal life is a significant burden for families which I consider in section 6.5. In section 6.6, I discuss the complex process of balancing the often conflicting demands of device care and everyday family life. I suggest that by working to realise the core aspirations of co-production, children, families, and professionals can work together to navigate these complex decisions (section 6.7). Finally, I offer suggestions for how this research can be used to improve IPC in the care of children with invasive devices in section 6.8, before closing with a discussion of the limitations of this thesis and my personal reflections.

7.1 The importance of pursuing normality for families

In this thesis, I argue that striving for normality was a key priority for families which was often in tension with the demands of IPC. As I describe in section 1.4, adjusting to life with a child with a serious illness requires children and families to make significant changes to their everyday lives. Families of children with chronic disease pursue normality as a mechanism for coping with the changes that are necessary to maintain the child's health.⁽¹⁶²⁾ Normality was such an important issue for children with invasive devices because the device threatened multiple aspects of their identity. This was *in addition* to the effects of chronic illness – the device and the IPC measures required to maintain it created an additional burden for children, making them different

from their peers. The child's ability to experience a normal childhood was compromised by the presence of the device. Normalisation was one way in which children and families could cope with the impact of the device.(242,243) Maintaining some degree of a normal life justified the pain and distress that the child and family had endured as a result of the medical condition.

Childhood is experienced both as a physical phenomenon, and as a social construct. Childhood is not merely a period of life that is defined by arbitrary age-cut offs. Rather it is a social construct: ideas of what it means to be a child, and what a "normal" childhood means are created through children's social interactions with the people around them, and the environment in which these interactions take place.(122,123) Concurrently, the physical impact of the device influences how childhood is experienced. Childhood is experienced through the continual defining of normal physical characteristics. Children are continually weighed, measured, assessed, and scrutinised to detect any deviations from the normal and expected patterns of development. To be a child in this context is to be continually compared against a standard of "normal".(122)

The normal childhood of children with an invasive device is threatened by their underlying disease, by the device itself, and by the care that is required to care for the device. Normal children are free from pain or discomfort; they may form part of a tight family unit with minimal interference from outside agencies; and develop a growing autonomy from their parents and carers.(122) The experiences of the children described by the children and families in this study set them apart from their peers, making them different.

When the care of a child takes place in hospital, parents can seek normalisation by separating the normal child at home from the abnormal/sick child of the hospital.(109) The boundaries between these different aspects of the child's identity are less clearly defined in the home environment.(245) In the case of a child with an invasive device, where much of the care took place at home, such separation was not possible for families.

The homes of families in my study were dominated by device care: the equipment required to maintain and care for the device was large and cumbersome. Homes were filled with large boxes filled with dressings and syringes. Families attempted to keep the boxes out of sight, hidden away in garages, behind cupboard doors, or underneath beds. Hiding equipment meant that families could try and create a more normal home environment for their child.(251) Concealing the signals of device care in this way often meant compromising space for personal possessions. Families worked to try and stop device care from taking over the family home. Despite their efforts, the sheer volume of equipment in the home meant that it could not always be hidden. Large pieces of equipment, such as suction machines and feed pumps, were kept within easy reach as they were used frequently throughout the day.

Once a child had an invasive device in place, the normal rules and boundaries that governed everyday life were altered.(245,270,271) Families could no longer rely on their own sense of what was safe or not for their child. Instead, families had to follow rules that were strange and different. An everyday task, such as bathing, acquired an additional set of rules for which families had no context. Common sense rules which children and families had followed to this time were no longer sufficient to deal with the demands required by the device.(271) Rather than basing their framework for activities of daily life on their past experiences or those of their peers, families now had to form a new framework to adjust to life with the device.

Some professionals only saw the child in the hospital or clinic environment. As a result, they did not fully appreciate how much device care affected everyday family life.

7.2 Physical impact of the device in the body

The device was an abnormal breach in the structure of the child's body. The physical breach in the child's body represented the way in which social boundaries were breached.(272) Parents found the appearance of the device and the way it changed the appearance of their child's body traumatic. Children's bodies are often portrayed as pure and untouched, undamaged.(247) A child's skin is usually intact, protecting the body beneath. Damage to the skin is usually associated with some kind of injury that is hurting the child, and thus the integrity of the skin is an indication of the health of the

body beneath.(123) Unlike the temporary bruises of childhood, the device formed a permanent breach in the child's body which was strange and unfamiliar. By agreeing to have the device inserted, the parents agreed to their child's body being damaged in a way that was abnormal.(246) The insertion of the device was an indication of the child's health needs that might otherwise have remained hidden beneath their skin.

Children and families accepted that the device was part of the child's body, and thus part of the child. However, the device was also seen as an alien piece of equipment which had resulted in a permanent change to the child's body and their identity.(247) The device was simultaneously alien, **and** part of the child and thus the family. Families acknowledged the advantages of the device for their child while at the same time feeling that their child had been changed as a result of the device.(246)

The physical body is particularly important to children as they experience their body and themselves as being the same entity.(123) Childhood is a time of biological and sociological change.(254) Children develop their sense of self through a growing awareness of their own bodies.(255) Thus changes to the body, such as the insertion of a device, will affect their sense of self.(246) The insertion of the device transformed the child's physical body; it also changed how the body was experienced by the child and by others around them.(246) Changes in the body meant that children were perceived differently by those around them.(248) Parents became more vigilant and more concerned about the child's vulnerabilities. Children's identities were not only altered by the physical presence of the device in the body, but also by the subjective feelings that having the device generated.(257)

The sense of self is unique to each individual and depends on the interactions with other people in everyday life. As children interact with the world around them, they develop a sense of self that depends on the context of their everyday lives.(255) The sense of self is constructed through the views and reactions of others towards the individual, and also in the way that the individual reflects upon themselves.(246) As I have described, the care of an invasive device affects all aspects of everyday life for children and their families, and thus the child's sense of self. Disruptions to the physical body changed children's idea of self, and changed their identity.(257) Pursuing a normal childhood was a way for children and families to mitigate these effects.

A child with an invasive device was exactly that – a child primarily who also had an invasive device placed. These children faced similar childhood challenges to their peers, such as arguments with their friends and parents.(258) Children and families were at pains to point out how little the child’s life was restricted by the device.(109,244) Children were seen, by themselves and their families, as normal apart from the care required by the device and their medical condition. In this way, the child was separated from the device, and normalised.(243)

7.2.1 Changes in the child’s body affect their sense of self

Part of belonging to a society is to adapt the body from its unaltered form to one which conforms to the expectations of that society – a process described as “bodywork”.(256) A sense of self is formed through the continual interaction of the body and the experiences of everyday life.(257) Children continually compare their bodies to their peers, looking for differences and making adjustments to conform to the group expectation.(255) The bodywork of children with invasive devices in my study varied depending on their experience of device insertion. Some children had had the device from an infancy, thus their construct of themselves was one in which the device was integral to their sense of self. These children developed a gradual awareness that they were different from other children. As children grew older, they began to compare themselves with other bodies in their immediate circle. This form of bodywork is undertaken by all children – however, the work and effort required is greater for some children.(255) This is the case for children with invasive devices. Children recognised that the device made their bodies different from other bodies. However, this awareness paralleled other awareness of difference such as gender, age, and hair colour. Some children made associations between the device and other body characteristics, stating that boys had “tubies” and girls didn’t, or that “tubies” and “wigglys” would be removed when they grew older as adults did not have invasive devices. These statements reflected their reflections on their own body, and on the bodies of others. Younger children compared their bodies to those of their immediate family, reflecting the relative importance of family members at this point in the life cycle.(249) As children grew older and moved outside their family circle, other persons became more

important to the child and they were exposed to a greater variety of bodies, and realised that the device was something different.

Children's bodies were changed by the device, and this could be particularly problematic for children who had the device inserted later in childhood. They sometimes struggled to adjust to the new sense of self that resulted. The child's body became different from how they had experienced it before the device was inserted, and how their altered body compared to other bodies.(257) Other physical changes to the body, such as menopause or puberty, result in an enduring change in the sense of self.(257) The impact of device insertion was different to the other changes seen with menopause or puberty however, as it was not a 'natural' change as part of the life cycle. As one father explained, the device was an obviously medical alteration for which he had no frame of reference. While other bodily changes were seen as normal or expected, the insertion of a device could only be seen through a medical framework.(246)

The device also affected the child's sense of self by removing the control that the child had over their body. Rather than acquiring greater independence and control over their actions as they got older, children's lives were restricted by the need for device care. Device complications such as infections were unpredictable and could significantly disrupt the child's life. The child's body could change rapidly from well to unwell. Children could not control their own bodies or predict when this disruption to their life would occur. This lack of control further threatened the child's sense of self.(243,257) The bodily changes caused by device insertion were further emphasised by the change in everyday activities which resulted from the need to keep the device clean. The trauma caused by first seeing the device was reinforced by the need to adapt daily activities to accommodate the device.(246)

Thus the insertion of an invasive device disrupted the normal experiences that the child might otherwise have, and altered how that child and their family experienced everyday life.(245) The device breached the physical part of the child's body, but also affected the interactions with the social world which allowed children's sense of self and identities to develop.

Following IPC practices affected the everyday, and thus threatened the child's self-image.(249) If families adhered fully to IPC practices, then they lost even more control over their everyday lives. Restrictions on activities furthered impacted on the sense of self, and the suffering that resulted.(249) Children wished to be seen as normal, but required additional help with device care in order to achieve this.(266) The restrictions of device care affected social interactions between children and their families and peers.(257)

7.3 The presence of the device makes children more vulnerable than their peers

Vulnerability is seen as an essential component of childhood. Children are often presented as innocent and vulnerable beings in need of protection. (123,261,273,274) The vulnerability of children stimulates adults to protect them, which can in turn limit their experiences and scope for autonomy.(123,261) The presence of the device further added to the perceived vulnerability of children.

7.3.1 Vulnerability of the body restricts children's experiences of childhood

The device made the child's body more vulnerable. Restrictions imposed to protect the child from infection limited children's social interactions, in addition to the limitations imposed by their underlying medical condition.(245,248) Activities like playing with their friends or in school playgrounds became fraught with risk and fears of injury. As a result of the device, the child's body was viewed differently from that of other children. Children's bodies are usually resilient and able to withstand the rough-and-tumble of childhood play. Their bodies may be temporarily injured or damaged during play, but their bruises heal readily. Such injuries are seen as a normal part of childhood.(264) Injuries were a different matter for children with invasive devices, whose bodies were already vulnerable because of their medical condition. Rather than a normal part of childhood, injuries were to be avoided in case the device was damaged and harm caused to the child as a result. The device disrupted this sense of the normal resilient childhood body, bringing children and families in close contact with serious illness and the prospect of death which was normally distant and remote.(245) Despite these risks, parents supported their children to play by supervising their activities, and improvising

protective coverings for the devices. In this way, parents took on another burden themselves, but allowed their child some normality.

This perception of vulnerability has particular relevance to children with additional medical needs, such as an invasive device. Children who have additional health needs are seen as more vulnerable than their peers. This perceived vulnerability of spills over into other aspects of their lives which have nothing to do with their health. Children with disabilities, for example, are portrayed as victims who need to be protected by society. They find themselves under closer adult supervision when performing the same tasks as their able-bodied peers.(108) Healthy children are encouraged to take small risks as part of their everyday lives. This is not the case for children who are unwell who are expected to be less active or engaged than their healthy peers.(123) They are made different by their physical needs and thus are separated from society.

Children with invasive devices were made both more, and less childlike by the care they required. The device meant that they were physically vulnerable, and dependent on adults for care needs. This correlates with the construct of children as vulnerable and fragile beings, whose physical immaturity places them at risk in an adult world. Vulnerability is seen as an essential characteristic of childhood, influencing decisions about children at all levels in our society.(122,266) Thus, children with invasive devices fulfilled the expectation of children as vulnerable. However, for most children, the construct of the weak and vulnerable child is tempered by the expectation that children will grow older, become physically stronger, and less vulnerable as time goes on.(123)

The families in this study could not assume that their child would progress in this way. The child's medical diagnosis meant that this future was uncertain. Children who are different are deemed to be more vulnerable than their peers (266); children with invasive devices were considered additionally vulnerable. Children with invasive devices were more childlike in their vulnerability, and less childlike as their social development and growth of independence was limited. The journey through normal childhood was interrupted both in the expected physical robustness of the child, but also in the social construct of childhood as a gradual progression towards strength and autonomy.

7.3.2 Loss of autonomy

The perception of children as particularly vulnerable compromised their developing autonomy. The presence of the device altered the child's physical appearance, making the child appear more vulnerable, and adults feel more protective towards the child.(123) IPC practices enhanced this feeling of protection: families were constantly reminded of the vulnerability of the child's body and the threat that everyday practices posed to the child. Children were unable to take control of their own bodies in the same way as their peers because of the requirements to maintain the device.(257) Rather than being seen as children *en route* to becoming autonomous adults, the continual demands of device care altered the image of children.(249) Children's sense of self and identity as vulnerable and dependent were continually reinforced by IPC practices.

The presence of an invasive device meant that children could not develop their independence in the same way as their peers. Childhood is seen a period of gradual transition towards being independent adults.(258) When a chronic illness affects every aspect of everyday life, the normal transition phases in life are inhibited.(245) The biographical disruption that affects children and young adults with chronic illness is well described.(243,249) Children with invasive devices were unable to participate fully in childhood activities that would ordinarily signal a growing independence and their progression towards adulthood, such as school trips without their parents or being left alone with a baby sitter. They were trapped at a certain stage of social development as a consequence of the device.(243)

In addition to the restrictions on children's activities, the device interfered with children's autonomy in more subtle ways. Children use their bodies in everyday life to carry out small acts of defiance against adult authority. Adults continually remind children to use their bodies in ways which are culturally acceptable, by sitting still or being quiet.(262) The presence of an invasive device impeded this part of normal childhood behaviour by imposing further restrictions on the child's body and how it could be used. Rather than playing with the device or "fiddling" with the ends of the tubing, children (in the main) enforced their own good behaviour. On occasions, children did use their bodies to resist device care. Children could kick, scream, and run away in attempt to avoid painful device care, such as dressing changes. Despite this

resistance, children saw compliance with device care as part of their body work. However, they did not have to engage or take an active role in the care of the device. Some children refused to talk or make eye contact when device care took place, or turned their back and walked away when the device was mentioned. In this way, children used their bodies to demonstrate their resistance to device use and care by withdrawing from the situation.(261)

The restrictions on the child's transition to greater independence also restricted the parents' development. The role of parents in society is to produce autonomous individuals who are no longer vulnerable nor reliant on others for their care.(247) As the child develops, the role of the parent also evolves over time. Caring for children as they approach adulthood and beyond is not viewed as part of the normal life-course for parents.(258) For some children with additional needs, the role of the parent is constricted. Parents struggled to find time away from the child in case they developed a device-related complication which required the parent's expertise to manage. Thus the development of the parent was restricted alongside that of their child.(275)

Care of the device also affected the autonomous functioning of the family unit. Adults take responsibility for the child's care – but this is usually contained within the family unit and within the privacy of the family home.(122) Children with invasive devices received care from a vast number of different adults, both in the home and outside it. Families shared responsibility for the child with professionals, breaching the normal family unit. Where families had access to respite care in the home, the privacy of the home and the family unit was compromised.

7.4 Children experience stigma as a result of the device

Stigma was a considerable emotional burden for children with invasive devices and their families.(258) Both the appearance of the device, and the way in which the device was used made the child's difference apparent. As a result, children and families were excluded from the social world.(249) Children and families attempted to control who knew about the device, as the reactions of others were unpredictable.(243) Some children with invasive devices had little option but to be open about their device. For example, if the device was in a location which was exposed or needed frequent

intervention which took place in public. These children had a stigmatising characteristic which could not be concealed. Their social status had already been discredited.(251,252) The child's family were also made different by their relationship to, and interaction with the child.(247,251,252) This "courtesy stigma" meant that families were stared at in public spaces; strangers approached the child and commented on their appearance or asked intrusive questions. The device also restricted how children interacted with others, making their difference more apparent. Children with tracheostomies were unable to communicate using their voice; children who were gastrostomy dependent could not share family meals. This loss of function made the device apparent even if it was not visible.

Families assisted in this concealment by controlling the information that was shared with the outside world, allowing their child to "pass as normal" within their community. (252) Managing the information which would signal to others was one way in which children managed the stigma of an invasive device. Some stigmatising characteristics were therefore evident and not concealed, while others (such as the device) were hidden. The fear of stigma was not confined to strangers or casual acquaintances. Stigma also affected whether children revealed their device to close family members.(245) Another girl was comfortable with her parents seeing her device, but refused to allow her grandparents to see it. How children treated the symbols of their difference depended on social circumstances.(247)

Families took other steps to manage information about their child's device, choosing how much information they wished to reveal and under what circumstances.(252) They rehearsed explanations of the child's device and why it was used so that children could explain to their school friends. In this way, families could control how the information was shared, even if the device could not be concealed.(246)

Device care added to the stigma symptoms of children with invasive devices.(247) The demands of IPC meant that additional care had to be carried out. Some devices could remain hidden until such time as IPC care needed to be carried out. Where device care failed, the private world of children could be thrown open.(246) Device site infections which leaked onto clothing and seeped through dressings were hard to hide. These social *faux pas* affect the self and identity. The child and the families' roles in society

were restricted as a result.(257) Using the device made the child different in addition to the changes imposed by the device.(247) Carrying out IPC practices served as a continual reminder to the child that they were different, even though the device could be hidden away and few signs visible to the outside world.(257)

7.5 The price of normality

In this context, where device care compromises so many aspects of normal childhood, it is hardly surprising that families put so much emphasis on maintaining normality: it was a major form of work. Normalisation and resisting that which made them different were ways in which children coped with their device (243,271), even though infection control could be compromised as a result. Children could participate in many normal activities – but such participation was not straightforward.(244,245) Ensuring that children had social contacts was time and energy consuming for families. These social contacts helped reinforce the child's self.(249) The children's specific needs meant that they could not simply attend normal social activities without significant work by their parents.(108,244) Families tried to integrate the child's needs into a pattern of life that was normal for that child, and which fitted with the family.(244) By mobilising their resources, parents could maintain some normality for their family.(245)

7.5.1 Additional burden/workload

Families put a lot of time and energy into managing their child's experiences, and integrating them into their community.(243) By managing these experiences, parents were able to create a space where their child could participate in normal community life.(251,252) Taking on additional burdens, such as taking bloods from a central line, meant that parents could minimise the impact that device care had on their families. Parents supported their child's admission to school by providing device care and reassurance for teachers. As the families in this study found, coordinating the services needed to maintain any degree of normality took a huge amount of time and energy.(108)

Elements of IPC were also affected as families sought to allow their child everyday experiences while maintaining a clean environment. Participating in these activities could actually be more isolating for children with invasive devices because the need to

maintain infection control restricted their interactions with others.(108) Attempts to integrate children with invasive devices into “normal” childhood activities required large amounts of work to be undertaken by parents – this work was rarely recognised by professionals.(275)

Children with invasive devices were supposed to follow a package of IPC measures to maintain device sterility. However, the impact of carrying out these measures was rarely considered by professionals. This lack of understanding is not a unique finding in this study. In a study of children with asthma, Prout et al. described how little was known about the impact on families of carrying out lifestyle changes that professionals suggested.(244)

7.5.2 Emotional/cognitive burden

Normalisation of children with invasive devices meant that parents had to be prepared to take some risks. Children could not be “wrapped up in cotton wool” if they were to experience a normal childhood. Allowing children this normal childhood went against the desire to protect the vulnerable child. Vulnerable children are deemed unable to gauge risks or to make reasonable decisions (266) – children with invasive devices were more at risk from normality than their peers. Parents shielded their children from their vulnerability by continually looking for potential risks and threats to the child, balanced with the needs of the child and the family.(275) Device care in the context of a normal childhood was a relentless emotional and cognitive burden for families.

Prioritising device care in the community setting meant that families had to see themselves as vulnerable in their daily lives, thus adding to the emotional strain already experienced.(139) Families who undertook healthcare tasks for their children were in the position of both observing, and potentially contributing to an adverse event. Parents who provided healthcare for their children were thus “first victims” as the direct sufferers of the consequences of an adverse event. Parents were also in the unique position of also being “second victims”: the healthcare provider involved in the event.(265) Increased awareness of errors has potential to damage the relationship of trust between professional and patient.(110) Second victims of medical errors experience emotional turmoil that affects their professional role as well as their personal

wellbeing.(265) This emotional vulnerability may explain why some participants in community safety initiatives to reduce device-related infection find aspects of these programmes challenging, and thus withdraw.(96)

As well as forming their own sense of “normal” symptoms, families had to recognise when these patterns changed, which was not simple. Families had to re-frame the symptoms in order for them to be recognised as something unusual and serious.(244) One example of this is how a gastrostomy changed after a child had been swimming – the family had to decide if the increased discharge was a normal response to the immersion in chlorinated water, or the start of a gastrostomy site infection. Carrying out normal activities made it harder to detect infection, further adding to the cognitive burden of families.

7.5.3 Role strain

Providing device care meant that parents had to assume dual roles: both parent and carer to their child.(164) Parents had to balance their roles as promoters of normal family life (247) against their role of keeping the child healthy.(264) IPC practices threatened the child’s normalcy and restricted their access to a normal childhood. Parents were supposed to protect their child’s health by following professional advice: consenting to the device being inserted, carrying out IPC practices rigorously, and restricting their child’s exposure to day to day risks of infection. However, all of these practices went against “normal” parenting. Rather than protecting their child or comforting them, parents had to undertake painful procedures such as dressing changes to keep their child safe (275), and control their engagement in ‘normal’ activities of childhood, leading to a conflict between the role of parent and carer in device care. While professionals were able to maintain a level of detachment when carrying out distressing IPC practices, families did not have this luxury.

The change in role from parent to carer exacerbated the loss of self that parents experienced.(249) Parents managed this tension by seeing the carer role as an extension of parenting. A “good” parent would go to any lengths to ensure that their child received good care (264), including taking on highly technical tasks. Parents felt that there was little choice but to provide this care, as without it, the child would suffer.(275)

Families who could access their child's central line or change a tracheostomy tube in hospital were accorded more respect by professionals, thus reinforcing the importance of the carer role.(275)

7.6 Finding the balance

IPC practices and device care were disruptive to the life of the child, and to the family. Families and professionals were torn between wanting to protect children from the impact of device-related infection, and the desire for the child to have a normal childhood. As I have explored, both the insertion of the device and the ongoing demands of device care to maintain IPC restrict the child's access to a normal childhood. These two demands were in continual tension with each other. The demands of the device altered the child's self-image and their identity in the social world.(249) Infections were unpredictable and occurred at any time affecting family holidays and birthday parties. This uncertainty affected every aspect of the child's life.(270) Children lost control over their bodies because of the device (257) – performing everyday activities such as swimming or going to soft-play centres helped children and families regain some control. By striving for a normal childhood, families reinforced the identity of their child as normal, and could counteract this altered identity of the child as “different”.

Trying to maintain device care through IPC practices in the context of a normal childhood was not without its cost. Families of children with invasive devices strove to maintain a sense of normality and to present their child as normal, especially in the family home.(109) IPC measures interfered with this sense of normality by making normal and everyday activities more challenging. Parents and children developed technical expertise to make the care of the device a part of everyday life. Device care permeated every aspect of daily life and could never be forgotten.(246) However, IPC was just one aspect of the care of the child. Families were highly motivated to decrease adverse events such as infections, but faced competing pressures in their lives which affected their ability to carry out care safely.(143) They had to decide when IPC was a priority, and when it had to fall by the wayside. Making these decisions involved additional cognitive work for families.(258) Trying to live a ‘normal life’ while maintaining IPC was a relentless burden for families.

7.6.1 The importance of a 'normal life' is influenced by the different experiences of families and professionals

A key theme throughout this thesis is the gulf between the experiences of families and professionals in the care of the device. This gulf leads to differences in perception of how a 'normal life' with an invasive device is lived between professionals and families, and arises even before the child has the device inserted. A consistent finding in this study was that device insertion was a physically and emotionally traumatic time for children and families which resulted in significant disruption to their lives. By contrast, professionals viewed device insertion as a routine part of the child's care which facilitated medical and nursing care of the child. Device insertion was seen as normal within the context of the child's medical needs, rather than being seen as a disruption to their everyday life.

Although the period around device insertion was traumatic for families, the difficulties of coping with the device in everyday life extended far beyond this time. The insertion of an invasive device represented a further challenge to the vision of a normal childhood which families envisaged for their child. Despite the challenges posed by living with the device, families worked hard to maintain some semblance of a normal life for their child, and to minimise the effect that device care had on normal family life. Families described the care of the device as something which fitted into their everyday lives around their existing routines such as getting dinner, going to school, or doing homework. The device was a means of facilitating other aspects of normal in the child's life: having a central line meant that the child avoided repeated needle-pricks for a blood test, or could have those blood tests performed by community nurses rather than going into hospital. Thus for families, the device was a phenomenon which had to be incorporated into their normal life.

Balancing the demands of IPC and maintaining a normal life required families to undertake a significant amount of work which was largely undertaken away from the gaze of professionals. As a result, many professionals remained unaware of the extent of the challenges that families faced in balancing the demands of the device against the need to maintain a normal life. Some professionals worked closely with families in the community. As a result, these professionals had a different perspective to their

colleagues based in the hospital. Community-based professionals saw the difficulties that families faced in everyday life to maintain device care, and had a greater appreciation of the impact that IPC practices had on family life. Notwithstanding their contact with families, the insight that professionals had into the impact of device care could only be partial.

When professionals did think about the impact of device care on the everyday life of the child, this was in the context of infection prevention. Professionals accepted that devices would be exposed to potential infection risks during the course of the child's everyday activities. Where there was a choice, professionals would prefer to use a device they felt had the least risk of infection from everyday activities. For example, if there was a choice between a tunnelled central line or a Portacath, inserting a Portacath would allow the child to continue their everyday activities and decreased the risk of device-related infection. However, the priority for professionals in this situation was not to support the child's normal life – rather, the aim was to minimise interference with the medical care and nursing that the child required by reducing the risk of infection and any resulting device complications.

The desire to maintain a normal life was tempered with fear of device-related infection for both families and professionals. Families and professionals prioritised these demands differently which may have been influenced by their different experiences of device-related infection. Most of the families in this study had no direct experience of life-threatening infection, although families were aware of other children who had become unwell or even died as a result. Parents were traumatised by what they had seen or heard; serious infection was seen by families as a low frequency but highly feared event. Less severe infections were also disruptive to the child and family, but more commonly experienced by families in my study.

Professionals had different experiences of device-related infection. Most of the professionals interviewed had been involved with at least one child with a serious infection who had needed significant medical intervention to survive. Some professionals had cared for children who had died as a result of infection. Professionals became distressed when they talked about the impact of infection on children, recalling clearly the details of their illness. They struggled to articulate just how ill such children

became as the infection was outside their normal frame of reference. Professionals were faced with continual reminders of the devastating consequences of infection, while families experienced this as a rare event. I suggest that the experience of device-related infection influenced the relative importance of IPC for professionals.

Children, families and professionals had different experiences of device insertion and the resultant impact on families. Although the pursuit of normality was important to both families and professionals, they viewed the relative importance of maintaining a normal life differently. Professionals viewed the use of invasive devices as a routine part of their work, and had little experience of the challenges that families faced daily. Children and families experienced device insertion and ongoing care in the context of their everyday lives. For them, device insertion was a traumatic event resulting in enduring changes to every aspect of their lives.

7.6.2 The pursuit of normality could make children's lives abnormal

Constantly striving for a normal childhood was not without its drawbacks. Families became accustomed to their child's needs, integrating these needs into the life of the family and creating a "new" normal. When the child came into contact with others and left the protection of the family circle, these differences were emphasised.(251) The aspects of device care which families had learnt to manage seemed much more serious when explained to an outsider. Families faced these explanations every time their child moved to a new environment or had new carers. As a result, integrating the activities which had become part of their everyday lives was continually challenged and made different. Some families described how the attempts to maintain normality resulted in these differences being emphasised. For example, if a child with a device required assistance to support them attending school, families had to complete forms detailing exactly what help was required. The normal activity of school attendance could only be facilitated by emphasising exactly how the child was different. Children wished to be seen as normal by their peers so that they could be accepted socially. Parents had to decide if their child would be better off in a mainstream school where the child could build closer relationships with their peer group, or in a school for children with special needs which was more accustomed to providing device care.(275) Additional support was available for children to facilitate their integration into mainstream education. In

order to receive this support, the children's needs had to be unpacked and made clear, which emphasised their difference.(108) Striving to live a normal life could itself make the child different.

The pursuit of normal had different meanings for different stakeholders in the child's care. Although professionals recognised the importance of maintaining normality for families, their understanding of "normal" could differ from that of families. In the case of invasive devices, families and professionals were keen to avoid device-related infections which were painful, and sometimes life-threatening. Repeated hospital admissions for suspected central line-infections were disruptive to family life, thus professionals were keen to promote device care which could reduce the threat of infection. By reducing the risk of infection, the disruption to the normal life of the child and family was reduced. However, the impact on the life of the child that resulted from device care was not always considered. The restrictions that resulted from these aspects of device care sometimes posed a greater threat to normal family life. In a study of children with asthma, Prout et al. found that families did not carry out the numerous recommendations that professionals suggested to them were supposed to maintain their "ordinary" life. Measures designed to reduce the risk of asthma attacks were recommended by professionals in a bid to reduce admissions to hospital and reduce medication use – both outcomes seen as out of the ordinary in a child's life. However, the measures suggested involved a significant change in the everyday life of the family and child. Pursuing one form of normality such as fewer hospital admissions could make life less normal for the family because of the restrictions that were imposed upon everyday life.(244) For children with invasive devices, the continual impact of IPC practices on everyday life could be more disruptive than infection.

7.6.3 Infections threaten normality too

Decisions around prioritising IPC practices or the activities of a normal childhood were further complicated by the impact of infections on the child, family, and professionals. Device-related infections also threatened the child's normality. Life-threatening sepsis was frightening and traumatic for all who witnessed it. Less serious infections also affected the child and family's normal life: suspected CLABSI resulted in hospital admissions for courses of antibiotics. During this time, children could not participate in

everyday family activities, and were in essence excluded from the family.(109) Families had other responsibilities outside the home which were in conflict with the need to support their child.(258) When a child was admitted to hospital for a suspected infection, parents had to sacrifice their other commitments, including leaving work, in order to be with them. Device-site infections were painful, and children struggled to take part in everyday activities as a result. Device-related infection disrupted the life of the whole family, not just the child with the device. The uncertainty and unpredictability of device-related infection itself made children vulnerable and threatened their coping mechanism of normalisation.(243) The physical body affected the child's social world.(257) Families and professionals had to consider whether strict adherence to IPC practices or device-related infections posed the greater threat to the child's experiences of normal childhood.

7.6.4 Managing tradeoffs

The way in which different families reacted to the threat of device-related infection and the need for device care varied greatly.(249) Some aspects of device care were followed rigorously by some families, beyond the standard advised by health professionals. Other recommendations were overlooked or disregarded. The observance of IPC practices was not consistent within families. Families made their own decisions regarding what signified an acceptable risk to device care. In this way, families were able to reclaim control over their family life where many other choices had been taken away from them. Regaining control enabled children and families to cope with the consequences of the medical condition and device insertion.(276)

Peer networks were an important resource for families to learn from others' expertise in managing tradeoffs. The child's illness and the demands of the device could lead to families feeling isolated.(275) Pre-existing peer groups were damaged, leaving parents with fewer social networks.(242) There was little spare time to spend building friendships in social settings as families were preoccupied with caring for the child. Parents felt they had little in common with other families whose children did not have medical needs and who did not share their experiences. Contact with families who had similar experiences meant that families felt more normal, and were accepted as part of

the community.(251) The real-world experience of other families added to the information that families could access from professionals.

When children first had a device inserted, families did not know what to expect. They had no points of reference on which to base their lives. Parents shared experiences of device care, including practical suggestions for maintaining IPC in everyday life. Early on in the journey, families did not know what help they would need or what professional support would be available to them. Families who were further along in the journey helped make suggestions for care by sharing their personal experiences.(275) Meeting other families with similar experiences helped put the child's needs into context and build a framework for family life.(109) Social networks supported families as they adapted to the changes in their lives resulting from device insertion.(248)

7.7 Co-production in IPC for children living with invasive devices

As I demonstrate in this thesis, the differences in priorities placed on the importance of IPC practices when compared to the experience of a normal childhood mean that device care is unlikely to be improved by imposing universal standards for device care in the community. IPC of invasive devices is literally coproduced by children, families, and professionals – they each contribute, and each has a role, and care of the invasive device is dependent on all parties. The aspirations of co-production models are, however, challenged by the different priorities and goals of the different stakeholders, in particular the conflict between IPC and the pursuit of normality, and how these are understood and valued by the different stakeholders. To achieve more effective approaches to supporting families to manage infection risks in the community, professionals need to work together with families to establish shared goals, and support good decision making about how best to achieve these goals. All the stakeholders need to work together to find solutions which are tailored to families' individual circumstances. This research has highlighted that coproduction, as I describe in Chapter 1, provides a framework through which IPC in the family home can be delivered, but achieving this requires recognition of the particular challenges to coproduction in this context. In this section, I describe three key characteristics or aspirations of co-production and the challenges faced in establishing these in children with invasive devices. First, defining shared goals which all partners agree to pursue. Second,

recognising the varying forms of expertise that all partners contribute to the care of the child. Third, building close networks between these partners to allow honest and open communication that is essential to pursue these goals. I close by reflecting on the working in line with a coproduction framework for IPC in the family home.

7.7.1 Shared goals

IPC is simply one aspect of the care of a child with an invasive device. Families and professionals both recognise the importance of maintaining a normal life for children with serious health conditions. The demands of device care and infection prevention can interfere with a normal life, therefore families and professionals must negotiate a balance between these competing demands. However, the priority that different groups place on the relative importance of ensuring a normal life for the child differs.

In order for children, families, and professionals to work together to address device care in the home, clear goals must be established which are shared by all parties.(184) If the endeavour is to be successful, partners should agree on what the challenges are that need to be overcome, the strategies to overcome these, and what outcomes they are trying to accomplish.(184,185)

Coproduction assumes that communities and networks will work together efficiently to achieve a shared goal. Applying this to infection control in children with invasive devices assumes that families, children, and professionals do in fact share a common goal – that of device sterility – and how best to approach it.(185) In practice this is hard to achieve: people may experience the same phenomenon differently. Agreeing on shared goals can prove challenging in view of the varied interests from the many stakeholders involved and the different motivations that each group will have for contributing.(191) This is a particular issue where children are concerned as adults may minimise something that children view as important, and ensuring that children's priorities and perspectives are included can be difficult.(123) Partners may not feel able to share their views openly: clinicians do not always appreciate what issues are important to patients, and may dismiss their views as irrelevant.(119) Outside the protective clinical environment, professionals may also struggle to express concerns regarding IPC practices in the home. In my study I found that by going into the child's

home, community nurses lost some of their authority and became more vulnerable..Nurses were limited in what they could say to the family in the home in order to promote IPC as they felt that their position was unsecure. When the child entered hospital, the professionals regained their authority, and could impose hospital-based IPC rules.(266)

Even when all parties agree on a shared goal, the extent to which this takes priority amongst other needs will vary. Professionals tend to assume that patients will make similar decisions to them if given the appropriate information. However, the information that patients use to make their decisions is more extensive and complex than professionals are aware of, and their priorities and the trade-offs they are willing to make will differ.(188) Families of children with invasive devices consider a wide range of different issues when undertaking device care. One aspect is the desire for the child to experience a “normal” childhood – this desire affects how children and families carry out device care. Supporting their child to experience a normal childhood was the overarching goal for many families. Device insertion was a disruptive and traumatic event for children, and normalisation helped children and families cope with the disruption. Families were keen to emphasise the normal activities that their children enjoyed, just like other children.(109,244) Rather than battling against professional opinion, families wanted to work with the support of professionals to maintain a normal life for their child.(243) The normalisation of medical work into the child’s everyday life helped reinforce the idea that the child could experience a normal childhood.

Complying with care procedures at all times, mimicking the zero tolerance approach seen to decrease device-related infection in the PICU setting imposed significant burdens on families and restricted the normal life of children, but families perceived that health professionals prioritised high compliance of families with standard IPC procedures. The families in this study often felt they had to undertake the work to demonstrate their compliance with IPC practices, or face the risk that their children would not receive the care that they required from the healthcare professionals involved.(191,277) It was difficult for families to discuss the conflicts and trade-offs they faced in day to day life, and get advice from professionals on how to make IPC work for them without disrupting their efforts to maintain normality as far as possible.

Notwithstanding the rhetoric around patient choice, much of the official literature refers to patients making “good” decisions, or “improving” their behaviour. Thus the decisions and actions of service users are still being judged by professionals and their worthiness appraised. Determining a level of risk that is acceptable to all parties will be challenging to professionals, who may see patient co-producers as an unpredictable resource.(183,186) Clinicians may believe that they have reached a shared decision with a patient but the patient view may be rather different.(119) As a result, families may not always disclose breaches of IPC practice, such as allowing a child with a central line to go swimming, to their clinician.

The complexity of the decision-making process regarding device care demonstrates that resolving device-related infections is not simply a process of improving training and education for parents, but about finding ways to open up conversations and establish ways of working towards shared goals. Co-production may be challenging for professionals: professionals may find that sharing decisions with patients will result in a loss of control over the child’s care.(183)

7.7.2 Recognising expertise

Technical expertise in the care of the device is not the sole preserve of professionals. Children and families bring considerable expertise to the care of the device, although this expertise is poorly recognised by professionals. Recognising and using the expertise of patients can be used to improve the quality of care that they experience, and improve health outcomes.(188) This can be seen in the treatment of insulin-dependent diabetes. Previously, insulin was administered at fixed times by healthcare professionals. Patients now administer their own insulin, adjusting doses and making decisions about their treatment based on their expertise of their illness and daily life. This has allowed patients to complement the treatment of a long-term condition and to develop treatment plans which are more meaningful to patients than previously.(191)

Although such self-management could be empowering in some cases, the parents of children with invasive devices sometimes found that their expertise was used to supplement or replace professional services outside the home. Children and families became so expert in device care that they provided feedback to professionals.(275)

Parents accompanied their child to school to support school staff with device care or in case of complications; some parents were expected to provide device care in hospital when their child was unwell adding to their burden at a time of considerable distress. Despite these expectations, the expertise that families provided was rarely acknowledged by professionals.

The expertise of children in making complex decisions about device care was also poorly recognised.(189) Children engaged in physical play at school which threatened their device, but which allowed them to participate in normal social interactions with their peers. A child's decision not to clean her gastrostomy at school was influenced by the need to protect herself and her family from the stigma associated with ill-health in her community. The decisions which children made were complex and sophisticated.

7.7.3 Building networks

Networks between patients, families and professionals exist at both at an individual level with the development of expert patient programmes, and in the establishment of networks of co-producers to improve outcomes in long-term conditions.(184)

Relationships between co-producers support information sharing between professionals and non-professionals, and allow co-producers to learn more about each other's expertise. Such conversations are essential if patients and professionals are going to agree jointly on outcomes, and how best to achieve them.(184-186) This degree of involvement and cooperative working can only take place if there is close interaction between the individuals involved. From this perspective, co-production may only take place if there is a long-standing, equal and reciprocal relationship between contributors.(186,191)

The relationship between families and professionals could influence device care and the response to infection. Relationships built over time allowed trust to develop between partners, supporting communication between families and professionals. It was easier for professionals to confront families about breaches in IPC practices once they had established a relationship. Conversely, the rapid turnover of respite carers in one home meant that the mother had no opportunity to build a rapport with the professionals. As a result, she struggled to persuade carers to follow IPC practices stringently.

Concerns about the endangering the relationship between family and professional may result in the reluctance of some professionals to discuss device care. Parents and professionals shared responsibility for the care of the child with an invasive device. Disagreements about the child's care had to be carefully negotiated. Disputes could lead to conflict which damaged the professional-family relationship, and affected the care of the child.(109) Thus both parties were keen to avoid this conflict, and some professionals did not discuss device care or IPC practices with parents or children at all.

7.7.4 Co-production in infection prevention and control

As I have demonstrated in this thesis, children, families and professionals work hard to carry out device care while negotiating different priorities in their lives. Families use their expertise to make complex decisions in the care of their child, which can be supported by a strong multi-disciplinary network of professionals. Drawing on co-production aspirations to develop an approach to addressing device-related infection would signal a change in how IPC in the family home is currently envisaged.

How far professionals can support children and families to take part in a co-production model of device care remains to be seen. Establishing what is of importance to children and families is vital to ensuring the success of the endeavour (183) but resolving these differences and agreeing shared goals will require open dialogue between co-producers.(185) Even when co-producers feel that they have agreed these goals together, professionals remain concerned that patients do not commit fully to these aims. Some professionals interpret co-production as a task that patients undertake **alongside** compliance with medical advice, rather than being a completely different approach to sharing care with families by establishing and working towards shared goals.(188) This raises concerns that such goals, and the actions needed to deliver them, may not truly be agreed between all parties. Co-producers must also recognise that forming a goal that meets patients' needs may result in a course of action that professionals feel is risky.(184)

Power imbalances exist in relationships between children, families, and formal services. These imbalances are a barrier to working in partnership, particularly where there is a fear of involving formal services.(189) Parents of children devices had to seem to obey

professionals' instructions or risk being labelled "non-compliant". Families were aware that their interactions with professionals altered the way in which they and their child were perceived. By behaving in a way which professionals found socially acceptable (such as using medical jargon), families gained acceptance in the professional world.(251) Their views and experience were taken more seriously, and families were able to mitigate the risk of perceived non-compliance. Several parents mentioned that the involvement of social services was used as a threat by professionals to enforce compliance with other treatment plans. Failure to adhere to adequate device care resulting in recurrent CLABSI has previously resulted in a child being taken into foster care in the UK.(277) Accepting families' decisions as valid will require a significant change from a culture that is used to professionals deciding which outcomes are important.(184)

The NHS has an obligation to provide care which complies with infection control standards, and to prevent avoidable harm from being done to the patient.(278) HCAs are now seen as an avoidable harm, and this is reflected in the way that the NHS has implemented infection control measures: breaches of IPC practice are expected to be reported by colleagues; incident reporting is promoted as a means of supporting patient safety; and patients and visitors are encouraged to challenge healthcare workers to ensure they have clean hands. But changes to ward infrastructure and training healthcare professionals in infection control may have little impact on the everyday care of children in the community: these measures may work well in the hospital setting, but have no relevance in the family home. The NHS constitution of 2015 states that care will be delivered in a "safe and clean environment that is fit for purpose" (278), but provides little clarity about how this can be ensured if the majority of the care of the child is delivered in the family's own home, or at the child's school. Little is known about how the NHS interacts with the local services and wider community in order to deliver on this commitment when these places are not envisaged as places to deliver healthcare.

At the same time the NHS is moving towards a model of patient-centred care, where patients and carers work in partnership with formal services and healthcare providers. Patients are increasingly asked to manage their own care; care is increasingly expected

to be tailored to individual needs. Children spend the majority of their time in the wider community, following lives that are not determined by their disease. Indeed, families of children with chronic illness may go out of their way to maintain normality in their home lives, even when this involves negotiating their way through the complexity of disease. Herein lies another dilemma for the care of these children: the NHS constitution also emphasises the importance of patient choice, and providing individualised care.(278) This emphasis on choice is in stark contrast to the wording of other guidance with regards to patient safety and infection control. There are tensions between the choice of patients and families to maintain as normal a life as possible in the face of the illness, and the need for strict control to protect their child from the risk of healthcare-associated infection; different stakeholders are often working with different priorities and goals. This tension is at the heart of the recommendation in this thesis of the need to take a co-production approach.

7.8 Implications for practice

I make suggestions for three main areas of practice that could improve the care of children with invasive devices. First, I outline areas where the education and training of families and professionals could be developed in order to improve the prevention and management of device-related infections (*Table 7.8.1*). Second, changes in service provision to support the care that families and professional groups provide (*Table 7.8.2*). Third, I suggest developing ways of working which encourage shared decision-making between children, families, and professionals (*Table 7.8.3*).

7.8.1 Improved education and training

The impact of device-related infection could be devastating for both families and professionals. Professionals explained that some of the most seriously ill children they had ever seen were those who were immunosuppressed and who developed bloodstream infection associated with a central line (CLABSI). However, they struggled to articulate these experiences to other professionals. As a result, their colleagues did not appreciate the severity of the child's illness, leading to potential delays in treatment. Nor were professionals always cognisant of the work that families undertook to care for the device. An improved understanding of the work that families carried out would allow

professionals to tailor the information and support they provided to the needs of the family. Sharing information which was relevant to the family's circumstances would enable families to make informed decisions and better manage risks. The need for improved training is not confined to healthcare professionals. Children spend a substantial amount of their time away from the family home (e.g. at school or nursery), and staff in these environments also need support. Families too need more practical guidance in order to carry out IPC practices in the home.

7.8.2 Changes to how services are organised

The relationship between families and professionals was important to allow trust to develop between partners, promoting open discussions about managing risks. Such relationships developed best where families and professionals had time to get to know one another through repeated encounters across long periods of time, and were threatened by frequent changes of staff. The large number of professionals involved in the child's care made communication challenging, which meant that there could be inconsistencies in the advice given to families, and delays in sharing information where there were concerns about the device. Where care was organised between different organisations, families sometimes experienced difficulties in obtaining adequate supplies to carry out safe device care. Where such supplies were available, the process of ordering and ensuring delivery was cumbersome, further adding to the family burden.

7.8.3 Supporting shared decision making

Numerous factors affected how children and families prioritised device care in their everyday lives. It follows that directing families to follow strict guidelines in the care of the device is likely to be unsuccessful. Professionals should work with families to establish their individual concerns and priorities in the care of the device, recognising that one size does not fit all. Support and information which is responsive to these priorities is more likely to be well received by families. Sharing clinical information with families would better support families to make safe decisions which takes account of their priorities in the care of their child.

Families develop expertise in managing the daily practicalities of device care. The expertise that families develop is an important resource which could be utilised to help novice families adjust to the reality of live with an invasive device. Currently, information is shared through informal networks of peers which arise largely through chance meetings in healthcare settings. By facilitating the growth of peer networks, professionals could support families to share pragmatic information. Professional oversight of these networks would also allay professional concerns about the quality of the information being shared.

Table 7.8.1. Improve the education and training of professionals and families

Issue to address	Objective	Action
Professionals were not always aware of the impact of device-related infection, leading to difficulties in team-working and delays in treatment.	Ensure that professionals understand the impact of device-related infections on patients and families	Use family and professionals experiences to support teaching on device-related infection
Some professionals had a limited appreciation of the challenges that families faced in carrying out device care in everyday life.	Professionals to develop a better understanding of the challenges that families face in IPC in order to support them to make safe, pragmatic decisions.	Training programmes for professionals to include time spent with children and families away from the healthcare setting, e.g. in the child’s home or at school.
Non-healthcare professionals lack confidence in caring for children with invasive devices.	Ensure that children have access to trained, confident support away from their home setting (e.g. at school).	Development of online resources which can be accessed as needed. Regular update days for non-healthcare professionals.
Families were given IPC guidance to follow, but not shown <i>how</i> to implement this in daily life	Ensure that families have practical methods of carrying out device care safely, making IPC guidance easier to comply with	Collate experiences of experienced professionals and families to create an accessible resource

Table 7.8.2. Changes to service provision

Issue to address	Objective	Action
Frequent changes of staff impair the development of trust between families and professionals	Support the development of a close working relationship between families and the community nursing team	Families should receive community care from a core group of two or three nurses who provide cover for each other during sickness or absence.
Care is provided in a range of different settings and by different providers, and it is important that all carers are aware of any concerns with the device.	Information about the child’s device and management plan should be shared with all carers, including parents.	Notes should be accessible by all partners in the child’s care, including the family. These could be as shared electronic records or as parent held notes.
The supplies required to carry out IPC practices are not readily available to some families.	Adequate supplies to carry out device care should be available and accessible to families.	Families should have access to disposable equipment necessary to carry out device care. An app could be developed to reduce the burden of ordering and coordinating supplies.

Table 7.8.3. Supporting shared decision making

Issue to address	Objective	Action
Families need information to be able to make considered decisions about their child's care.	Access to clinical information means that families can make informed decisions about their child's risk of infection, and can make plans accordingly.	Professionals should take active steps to share such information with families in order to support them to make these decisions. One example highlighted in this thesis is where nurses ensure that families know when a child's immune system is compromised because of chemotherapy.
The expertise of families in providing device care outside the healthcare setting is currently underutilised.	Make use of the expertise which families have developed to support novice families to provide device care at home.	Professionals to facilitate the development of peer networks to share information between families.

7.9 Limitations and suggestions for further research

There are several limitations to this research. Before embarking on any new research, it is important to address the limitations I discuss below. PPI would prove valuable in addressing these issues and providing pragmatic solutions. One limitation in this study is that the PPI discussions took place with a single individual who represented families of children with cancer within a single geographical area. Although this individual was a representative of a larger group of families, it is important to recognise that her views were the only parent views which I accessed and that these dealt with a relatively small group of children and families who had similar experiences of services.

7.9.1 Challenges with recruitment

Difficulties in recruitment were apparent from early on, and persisted despite considerable efforts to overcome them. These difficulties are well-reported in work with children with serious illness and strategies to best overcome these challenges remain unclear.(279) I had originally intended to recruit families through their clinicians (e.g. through hospital out-patient appointments or contact with community nursing teams). It transpired that this approach was not very effective for the reasons outlined in section 2.4.3 – indeed, only five families were recruited through this means. The remainder were recruited through adverts placed on social media or through contact with parent groups. Although this strategy proved effective in recruiting a greater number of families, this approach may have affected the diversity of the sample included in this study as families would have had to have been engaged with these communities in order to find out about the study. Feedback from families suggested that there were no concerns with the study or recruitment strategy. Rather, the difficulties with recruitment reflected the reality of their lives caring for a child with an invasive device, and the resultant constraints on their time.

I did not formally collect data on factors such as socioeconomic status or educational achievement, but such information was available during the data collection period. The majority of families recruited in this study lived in families where at least one parent was in full-time employment, owned their own home, and where both parents were educated to at least graduate level. Only two families were non-White British, and all families

spoke and wrote English. The diversity of the families included in this study is not representative of the wider population, and it is likely that the experiences of the families included in this thesis are not mirrored by all families where the child has an invasive device. Further research is needed to explore the challenges faced by families from a broader socioeconomic background than those described here. Recruiting families from different cultural backgrounds poses some challenges, particularly where there are concerns about stigma from their community – I was able to recruit one family through a snowballing approach – as such families may have little contact with parent groups or other networks. The experience of this one family suggest that there are difficulties in accessing support from both professionals and peers, thus making their experiences of device-care very different. Recruitment strategies could involve: a wider range of clinicians involved in the recruitment process; encouraging families to distribute the information amongst their peer groups (“snowballing”); and promoting the study in geographical areas of particular interest. Advertising the study in areas for all children (not only those with invasive devices) – such as playgroups, schools, and community centres – could mean that a broader group of families are included in future work.

A similar recruitment challenge was encountered in the professional participants and some professional groups were more represented than others. Much like families, professionals I contacted reported difficulties in finding time to participate in the study, despite their interest in the subject. Many of the participants took part in their own time – an additional intrusion to their home life. Organisations which were unable to provide their team members with time in the working day to participate did not feel comfortable asking professionals to commit their personal time to the project.

Some professional groups were identified by families, but proved difficult to recruit. No trained carers or care assistants outside of hospital (e.g. those employed under personal budgets or in schools) were included. Attempts to recruit carers were challenging as there is no registered body, and no database of individuals to approach. A future strategy could be to approach carers identified by families, or to contact individual agencies directly. Only one general practitioner took part in the study, leaving a significant void in the members of the multi-disciplinary team. In addition,

only one school-teacher participated, leaving this important area of the child's life relatively underexplored.

The professional groups approached to participate were identified from family interviews, and thus were dependent on their recollection and knowledge of which professionals were involved in supporting device care. Professionals who were not in direct contact with patients, or who families did not perceive as having a role to play in device care were therefore not included. A wider recruitment strategy, including all professionals who self-identify as supporting children with invasive devices would improve the understanding of this complex issue. These groups should be explored in more detail in future research.

Overcoming these challenges is not simply a case of providing funding to compensate for the time that families and professionals commit to research. Both groups had highly developed technical skills which meant that their caring responsibilities could not easily be handed over to others. PPI in this area could help to identify solutions to this challenge.

7.9.2 Approach to data collection

Data were collected through semi-structured interviews. Although this enabled me to collect a large amount of information in a relatively short period of time, it meant that I was reliant on recall by participants. An ethnographic study of daily life with the device would have revealed more detail about the care that each child received, as well as allowing more scope to discuss more challenging issues.(280) However, this would also have been more time consuming, would impose ethical challenges, and was beyond the scope of this body of work. Data were collected by telephone interviews with the majority of professional participants. Although this allowed me to recruit from a wide geographical area, there are limitations to the depth and richness of the data collected by telephone (described in section 2.5.3). It is possible that face-to-face interviews would have yielded more detailed and informative information than that gathered over the telephone.

The limitations of the recruitment approach and data collection methods have implications for the quality of the work. Theoretical saturation was achieved within the

data collected. However, I recognise that a broader selection of participants and more in-depth interviewing may have yielded new themes which did not emerge from these data.

7.9.3 Suggested areas for further research

Notwithstanding the limitations of this study, the work has highlighted several important areas for further study. It was clear from the experiences of some families that infections around the device-site as well as CLABSIs had a significant impact on the child's quality of life. Children suffered pain so severe that they were unable to sleep or to take part in their normal activities. Despite this, professionals appeared to have limited awareness of the consequences of device-site infections, although CLABSIs were viewed as significant events. This is in keeping with existing research which pays little attention to the impact of device-site infection on patients.(84,85,88,89) Further research is required to evaluate the incidence of device-site infections, and the impact that such infections have on children's quality of life.

Family participants were confined to the parents of children with invasive devices. Other family members, such as grandparents were not included although they are a part of the wider family and play a role in supporting families. During the study, it became apparent that siblings played a role in device care, acting to alert other family members of concerns or carrying out technical tasks. The role and impact of siblings in device care and IPC has not been studied, and this merits further consideration.

The shared experiences of other families was an important resource of practical information for both families and professionals in maintaining IPC. There is growing interest in the benefits that peer groups can bring to families of children with long-term conditions, yet the contribution of such groups to improving patient care is under-researched.(281) Rather than focusing on the social and emotional support, future research could evaluate the impact of sharing family experiences on the burden of carrying out IPC measures in device care.

Furthermore, the wide geographical spread of the participants (families and professionals) meant that I became aware that there were wide variations in how care was organised in different parts of the country. I did not investigate the organisational

and structural influences on device care in this study. Future research should survey existing care providers to establish how the care of children with invasive devices is organised, and to collect examples of good practice at an organisational level.

7.10 Personal reflections

On the effects of Klatchian coffee, a drink which *“strips away all illusion, all the comforting pink fog in which people normally spend their lives, and lets them see and think clearly for the first time ever.”*¹

Undertaking this PhD has been a Klatchian coffee moment in my life. As a professional, I approached this thesis believing that I had some insight into the experiences of the patients that I cared for in my work. After all, I became a paediatrician because I believed that children and families were important partners in their care and I wanted to work closely with them. I had flattered myself that I was good at communicating with patients and their parents and that I understood their concerns. I was wrong.

Initially, when I began to hear parents’ experiences of their treatment by professionals, I was disbelieving. I wanted to believe that the experiences that they related were unusual; that professionals *did* recognise the expertise of families; that we made shared decisions and worked together... I continued working part-time as a paediatric registrar in a busy teaching hospital throughout the completion of this thesis. My experiences at work challenged my understanding of the data I had collected through the family interviews. I saw through my own practice that the experiences of the families I interviewed were not exceptional. Families described that their expertise was not considered valid by professionals, and that their attempts to contribute to clinical decision-making were brushed aside. I wanted desperately to believe that this did not happen – and yet I repeatedly witnessed teams of well-intentioned, caring professionals discuss children’s care and make plans for their future without involving either the child or their family in those discussions. I had thought that I involved children and families

¹ Quote taken from “Sourcery: A Discworld novel” by Terry Pratchett, 1988

in decision-making. I realise now that from the families' perspectives, I am far from doing this in practice.

Other moments during the writing of this thesis have been unexpectedly difficult. I found the process of writing about the impact of device-related infections on families and professionals traumatic. I have cared for children with life-threatening central line-infections – I *know* how sick these children can be, and yet I, like the professionals in this study, struggle to describe this to others. As I describe in section 2.6.2, it may be that these shared experiences meant that I was less rigorous in exploring what participants meant than I would otherwise have been. It may also have been that I was protecting myself from revisiting difficult experiences when I have been involved in the care of children with life-threatening infection.

The past four years have changed how I see my patients and their families. I hope that I am more appreciative of their knowledge and their expertise than I was before. I am very fortunate that I have a large and very diverse group of friends who are also patients and healthcare users. Their perspectives are a constant reminder of the importance of trying to understand their experiences, alongside the recognition that I cannot truly understand.

8 Conclusions

In this thesis, I have described the challenges faced when carrying out IPC practices in the care of a child living at home, where the care is distributed between family members and professionals. This thesis provides a novel perspective on IPC outside of the healthcare setting, and the challenges in reducing device-related infections. Ensuring that device care is carried out cleanly and safely when a child lives at home is not simply a case of strict adherence to guidelines. Rather it is a process of highly sophisticated decision making, balanced against the desire for the child, and family, to live as normal a life as possible. The desire for a normal life is tempered by the fear of device-related infections which are a significant concern for families and professionals. As I describe in this thesis, the impact on all parties is traumatic and significant. Nor are families ignorant of the tasks of the procedures to be followed when performing device care. Lapses in IPC practice occur because preventing device-related infections is not the sole priority for families, nor is it always technically or practically feasible.

Living with, and caring for an invasive device has a significant impact on the lives of families and children. This impact pervades every aspect of their lives, forcing them to create a new normality that incorporates the device. In a world where everything was changed by the device, pursuing normality was one way in which families could retain some control. Normality was also an attempt to mitigate the stigma which children, and their families, experienced as a result of performing device care.

Creating this normality is time-consuming as well as being physically and emotionally draining. Yet families continue to take on additional burdens so that children can go to school, go swimming, and play with friends – the normal pastimes of childhood. It is not possible to maintain total adherence to IPC practices in this settings, and families do not attempt to. Instead, they use their expertise to decide which elements of IPC can be compromised while keeping the infection risk low.

Professionals in this study, in the main, did not appreciate the complex processes which underpinned families' decisions. Nor did they recognise the work that families had to perform to pursue a normal life for their child. I argue that this discrepancy arises in part because of way in which professionals encountered children and families in their

working lives. Professionals saw children in healthcare settings, or during healthcare activities, and not in the course of their everyday lives. The perception of what “normal life” meant to families, and the work needed to maintain this normality was limited to these encounters. The burden that families carried was largely unseen and unrecognised as a result.

Normalisation is well described in the literature on children with chronic illness, but has not been previously explored in the context of IPC in the home. As I have described, normalisation is important for the wellbeing of children and families, allowing them to cope with the impact of both the disease and the demands of the device. Families will at times prioritise normality over IPC measures in the best interests of the child and wider family. Reiterating guidance to families on IPC and device care in this situation will only have a limited impact. Nor will it address the issue that strict adherence to IPC practices poses risks to the child’s wellbeing, their sense of self, and their place in the social world. Addressing device-related infection in children living at home, therefore, is not simply a case of providing more training or guidance on device-care for families. Rather, an approach is needed which recognises the multiple competing pressures that families face, and which makes best use of the skills and expertise of all partners who care for children with invasive devices. Families and professionals must work together to perform IPC in ways which are pragmatic, feasible, and relevant to individual families. Co-production models offer an approach through which families and professionals can work together to establish shared goals in device care, using the expertise of all carers, and working together in networks to ensure the best care for the child.

9 Appendices

9.1 APPENDIX A: Example of search strategy

Database: Ovid MEDLINE(R) without Revisions <1996 to January Week 3 2013>

Search Strategy:

-
- 1 "Equipment and Supplies"/ (5681) **this is the subject heading for medical devices**
 - 2 exp Ambulatory Care/ (20777) **SH for non-hospital care**
 - 3 exp Home Care Services/ or exp Community Health Services/ or exp Primary Health Care/
or community care.mp. (305368)
 - 4 2 or 3 (322999)
 - 5 infection control.mp. or exp Infection Control/ (29548)
 - 6 exp Infection/ or infection.mp. (608129)
 - 7 pc.fs. (612219) **this is searching for any subject heading with prevention and control as a
sub-heading**
 - 8 6 and 7 (85053)
 - 9 5 or 8 (102911)
 - 10 4 and 9 (9472)
 - 11 limit 10 to "all child (0 to 18 years)" (4003)
 - 12 medical device*.mp. (5140)
 - 13 catheter*.mp. or exp Catheter-Related Infections/ (114334)
 - 14 4 and 13 (2098)
 - 15 limit 14 to "all child (0 to 18 years)" (412)
 - 16 1 or 12 or 13 (123387)
 - 17 4 and 9 and 16 (260)
 - 18 limit 17 to "all child (0 to 18 years)" (42)
 - 19 from 15 keep 3,7 (2)
 - 20 18 or 19 (43)
 - 21 central venous catheters.mp. or exp Catheterization, Central Venous/ or exp Central
Venous Catheters/ (8810)

- 22 cvc.mp. (1739)
- 23 cross infection.mp. or exp Cross Infection/ (25946)
- 24 21 or 22 (9557)
- 25 9 or 23 (115721)
- 26 24 and 25 (1929)
- 27 4 and 26 (60)
- 28 limit 27 to "all child (0 to 18 years)" (15)
- 29 19 or 28 (16)

9.2 APPENDIX B: Participant information leaflets

9.2.1 Information for children aged 4 – 7 years

<p>INFORMATION FOR CHILDREN (4–7 YEARS) VERSION 4: 27th May 2014</p> <div style="border: 2px solid yellow; padding: 10px;"><h3 style="text-align: center;">Jo and the device</h3><p>Can you help me tell Jo about the gadget?</p><p>Sometimes, doctors and nurses use a special gadget to help look after you. You might have one that helps with your breathing, or to give you food or medicine</p><p>We want to find out what it's like to have a gadget, and how to look after it. We're asking children like you, who already have a gadget if they can talk to us, so that we can tell Jo what it's really like.</p><p style="text-align: center;">Can you help us?</p><p style="text-align: center;">1</p></div>	<p>INFORMATION FOR CHILDREN (4–7 YEARS) VERSION 4: 27th May 2014</p> <div style="border: 2px solid yellow; padding: 10px;"><h3 style="text-align: center;">Why are we asking these questions?</h3><p>Looking after a gadget can be hard. We want to ask children who already have a gadget how to look after it. Then we can tell new children, and their mummies and daddies what they can do to look after their gadget.</p><p style="font-size: small;">"Hello! My name is Carmen and I'm a children's doctor"</p><h3 style="text-align: center;">What will happen if I say yes?</h3><p>If you say yes, I will come to your house when your mummy or daddy are there. I'll check that everyone is still happy for me to ask you about your gadget before we begin. Then I'll ask you some questions, and watch so I can see how to look after the gadget.</p><p style="text-align: center;">2</p></div>
<p>INFORMATION FOR CHILDREN (4–7 YEARS) VERSION 4: 27th May 2014</p> <div style="border: 2px solid yellow; padding: 10px;"><h3 style="text-align: center;">What questions will you ask?</h3><p>If you say yes, I will come and ask you some questions about having a gadget, and how you look after it. We might draw some pictures together, or bring Jo so that you can show me what it's like to look after your gadget. I'll also make a recording of what you say, to make sure I remember it all!</p><p style="text-align: center;">Do I have to say yes?</p><p>No, you don't have to answer any questions unless you want to. You can change your mind whenever you want to, even if I've already started asking you questions.</p><p style="text-align: center;">3</p></div>	<p>INFORMATION FOR CHILDREN (4–7 YEARS) VERSION 4: 27th May 2014</p> <div style="border: 2px solid yellow; padding: 10px;"><h3 style="text-align: center;">Are there any good or bad things about answering the questions?</h3><p>Some of the things we talk about might make you feel sad or upset. If you want to stop talking to me at any time, then that's fine. I'll only talk to you when your mummy or daddy are there.</p><p>Showing me how you look after your gadget could help teach other children (and their mummies and daddies) how to look after gadgets, and what kind of problems they might have.</p><div style="border: 1px solid gray; border-radius: 15px; padding: 5px; text-align: center; margin: 10px auto; width: 80%;"><p>Just ask if you have any questions</p></div><h3 style="text-align: center;">What if there is a problem?</h3><p>If you are unhappy about anything, then talk to your Mummy or Daddy first. If you want to ask me any questions, then you can do that.</p><p style="text-align: center;">4</p></div>

9.2.2 Information for children aged 8 – 12 years

INFORMATION FOR CHILDREN (8–12 YEARS) VERSION 3: 27 May 2014 1

 University of Leicester
University Hospitals of Leicester 

INFORMATION ABOUT A RESEARCH STUDY IN CHILDREN WHO HAVE INVASIVE DEVICES ("GADGETS")

Interviews & observation

WHAT IS THIS STUDY ABOUT?

This is a project about children who have special medical devices or "gadgets". Sometimes doctors and nurses use a special gadget to help look after you. You might have one that helps with your breathing, or to give you food or medicine. We know it can be difficult to look after a gadget and keep it clean, especially when you're trying to do lots of other things. We want to know how you look after your gadget, and what it is really like to have one.

Children like you who have gadgets can help us.



Before you decide if you want to take part, it is important that you understand why we are asking for your help, and what it would mean for you.

Please read this booklet carefully with your Mum or Dad. Talk to them about any questions you might have. Think carefully about the project before you decide if you want to take part, or not.

INFORMATION FOR CHILDREN (8–12 YEARS) VERSION 3: 27 May 2014 2



HOW CAN I HELP?

We are asking lots of different children with gadgets to help us. Your doctor or nurse thinks that you know about gadgets, and what it's like to have one. We want to know what you think about having a gadget, and what would help you and your family look after the gadget.



WHAT WILL HAPPEN IF I SAY YES?

If you say yes, I will come to your house when your mum or dad are there. I'll check that everyone is still happy for me to ask you about your gadget before we begin. Then I'll ask you to tell me about how you look after your gadget.

I'll also come to see you when someone else looks after the gadget, maybe at home or at school. I'll only come and see you when I've checked with you and your family that it's OK to do that.

"My name is Carmen and I'm a children's doctor. I want to find out more about looking after a gadget. Can you help me?"



DO I HAVE TO SAY YES?

No, you don't have to answer any questions unless you want. You can change your mind whenever you want to, even if I've already started asking you questions.

WHAT QUESTIONS WILL YOU ASK?

If you say yes, I will come and ask you some questions about having a gadget, and how you look after it. We might draw some pictures together so you can show me how to keep a gadget clean. If some of the questions are difficult or worry you, then you don't have to answer them. You can ask me to stop whenever you want.

I'll also make a recording of what you say, to make sure I remember it all!

If I come and see you at home or at school, I'll write down some notes about what I've seen. I won't write your name, or the name of your school though.



Anything you tell us will stay private

WILL YOU TELL ANYONE ELSE WHAT I'VE SAID?

We will usually keep what you tell us between you, your parents, and the people working on the project. Sometimes, we might have to tell other people if you tell us something that worries us, in order to keep you safe.

After we've recorded the interview, it will be typed up. We won't write down any names or places. We might use something that you've said to explain how to look after a gadget. If we do this, we won't use your name or any private things about you. This means that no-one else will know who said this. Your name won't be on any papers or on the Internet.

ARE THERE ANY GOOD OR BAD THINGS ABOUT ANSWERING THE QUESTIONS?

Some of the things we talk about might make you feel sad or upset. If you want to stop talking to me at any time, then that's fine. If you want, your mum or dad can stay with you when we talk.

Showing me how you look after your gadget could help teach other children (and their mums and dads) how to look after gadgets, and what kind of problems they might have.



WHO IS ORGANISING THIS PROJECT?

This project is being organised by the University of Leicester.

There are three people on the research team:

Carmen Soto is a children's doctor, and she is doing most of the research.

Carmen will be the person talking to all the children who are helping her with this project, and she will be the person who comes to watch you looking after your gadget too.

Mary Dixon-Woods and Carolyn Tamant are helping with the project.

WHAT WILL YOU DO WITH WHAT YOU FIND OUT?

We will use the things you tell us and show us to help us understand more about having a gadget. We will talk to different children, families, and other people who look after the gadget (like doctors and nurses) to get a good idea of what it's like trying to keep a gadget clean. Then, we'll put all these ideas together.

We can use this to help doctors and nurses understand what children need to look after their gadget. We'll also use it to tell children who have a new gadget (and their families) what the difficult things are about having a gadget, and what the best way to look after a gadget is.

This will help other children who have gadgets

"It's OK to ask lots of questions."

WHAT IF I'M A BIT NERVOUS ABOUT TALKING TO YOU?

If you have any worries about this project, then please talk to your Mum or Dad to start with.

If you have questions about the project, you can ask Carmen.

Your Mum or Dad will help you if you still have any worries. They can talk to Carmen too, or to Mary Dixon-Woods if there are any problems.

9.3 APPENDIX C: Topic guides

9.3.1 Topic guide for children



Topic Guide for Child Interviews

1. Tell me about how you look after your gadget? (What happens when you get up in the morning/get washed/get dressed/get ready for school...)
2. What happens with your gadget at school?
3. Do you go anywhere else where you have to look after your gadget? (Prompted if other activities/locations have been mentioned in parent interviews)
4. Who helps you look after the gadget?
5. Who can touch the gadget? Who helps you look after it?)
6. What are the good things about having a gadget?
7. Are there any bad things about having a gadget?
8. Is there anything you have to be careful about because you have a gadget?
9. Is there anything that you can't do because you have a gadget?
10. Are there special rules about the gadget?
11. Who's allowed to touch the gadget?
12. Is there anything you would change about having a gadget?

9.3.2 Topic guide for parents

Topic Guide for Parent Interviews

Background

What experience do you have of looking after a child with an invasive device?

Daily Life

1. Take me through your normal day with the device, from when [your child] gets up
2. What are your responsibilities for looking after the device?
3. Who else looks after the device?
4. What about when [child's] not at home?
5. Do you get help from anyone else with looking after the device?

Challenges

1. What are the challenges of looking after a child with an invasive device at home?
2. What kind of training did you get about looking after the device?
3. What kind of information or support did you get?
4. What about before the device was put in – did you get a chance to ask questions?
5. Did you understand what it was going to be like for you and [child], having an invasive device?

Partnership

1. Who works with you to look after the device?
2. Do you get help from anyone else with looking after the device?
3. How does [child] help with looking after the device?

Risk Perception

1. Are device-related infections a worry for you?
 - a. Do you know anyone who's had a device-related infection?
 - b. Has [child] ever had a device-related infection?
2. What are your worries about the device getting infected?
 - a. At home?
 - b. Outside of home?
 - c. When the device is used?
3. Where do you think most device-related infections come from?

Future Directions

1. What do you think would help families to look after a child with an invasive device?
2. What do you think would help reduce device-related infections?

9.3.3 Topic guide for professionals



Topic Guide for Interviews with Formal Services/Professionals

Background & Experience

1. What is your job role?
2. What experience do you have of looking after children with invasive devices in the community?

Challenges

1. What are the challenges for families looking after a child with an invasive device in the community?
2. What are the challenges for professionals caring for families in the community where the child has an invasive device?

Partnership

1. Who is responsible for looking after the invasive device?
2. How do you work with families to look after the device?

Risk Perception

1. How big an issue are device-related infections in the community?
2. How concerned are you about device-related infections?
3. How concerned are the families about device-related infections?
4. Where do most device-related infections come from?
5. What kind of infections risks are there for child living in the community with an invasive device?
6. Who's responsible for keeping an invasive device free from infection?

Future Directions

1. What would help families look after a child with an invasive device?
2. What would help other services (such as yourselves) look after a child with an invasive device?
3. What more can be done to reduce device-related infections in the community?

9.4 APPENDIX D: Additional tools to aid interviews with children

9.4.1 Role play toy with central line

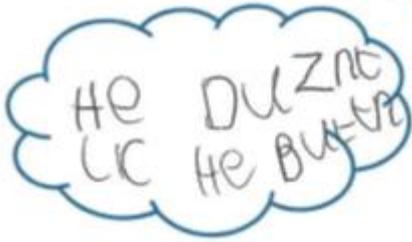


9.4.2 Worksheets to aid data collection



When will it be finished?

He doesn't like the button



Scared

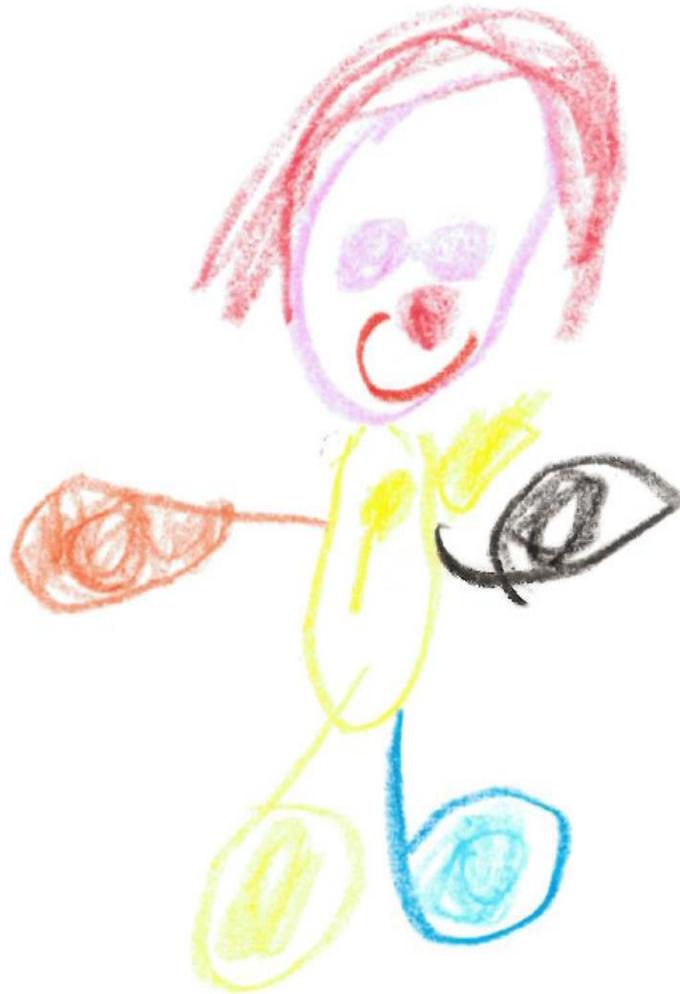
Sad



Fres

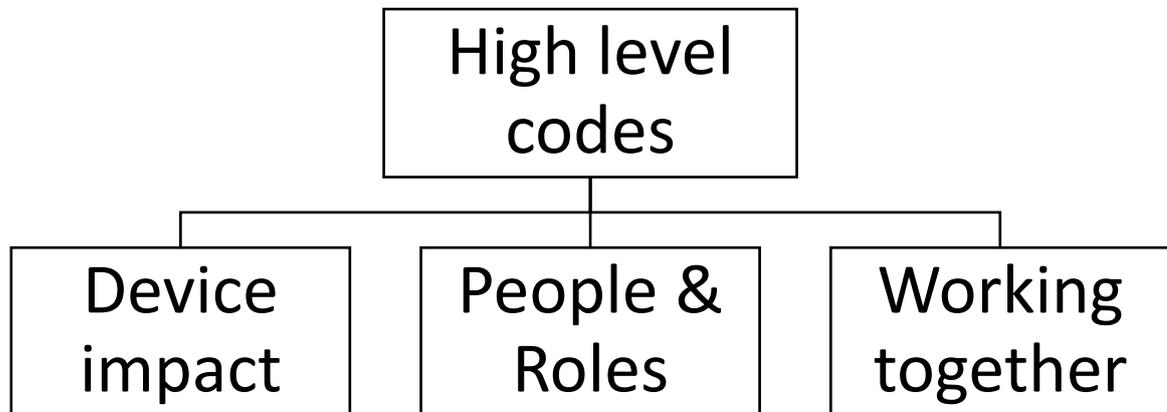


9.4.3 Child's drawing of herself with central line

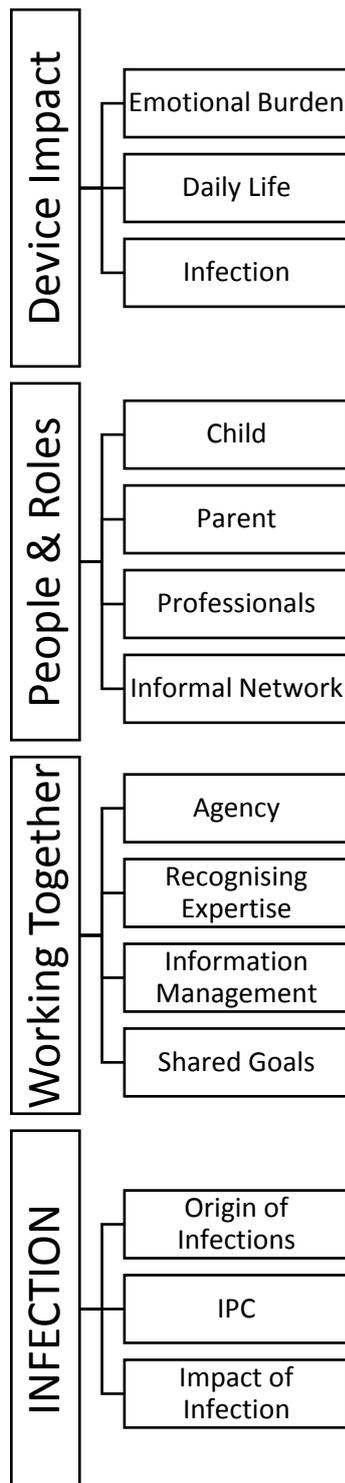


9.5 APPENDIX E: Examples of coding trees

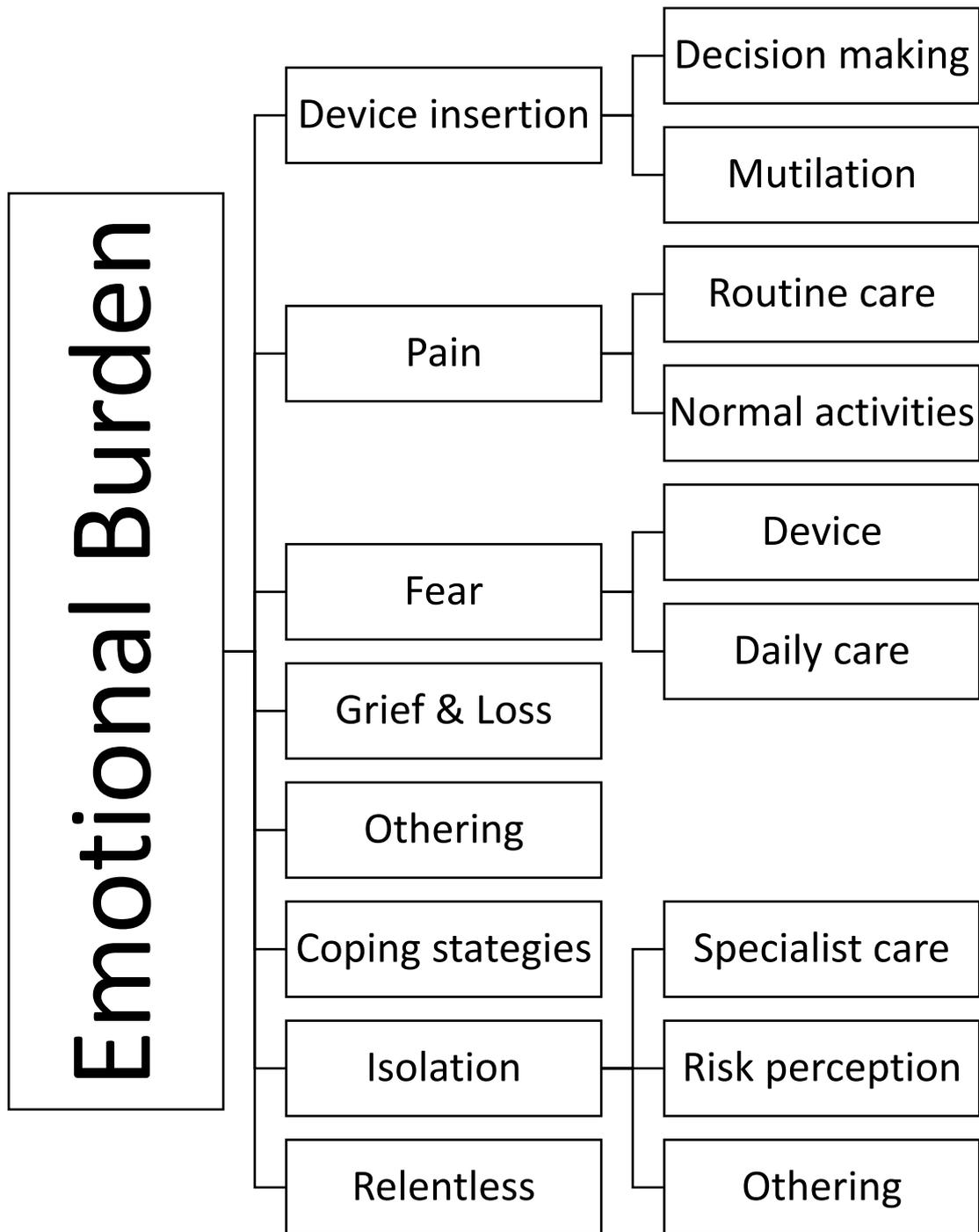
9.5.1 High level codes

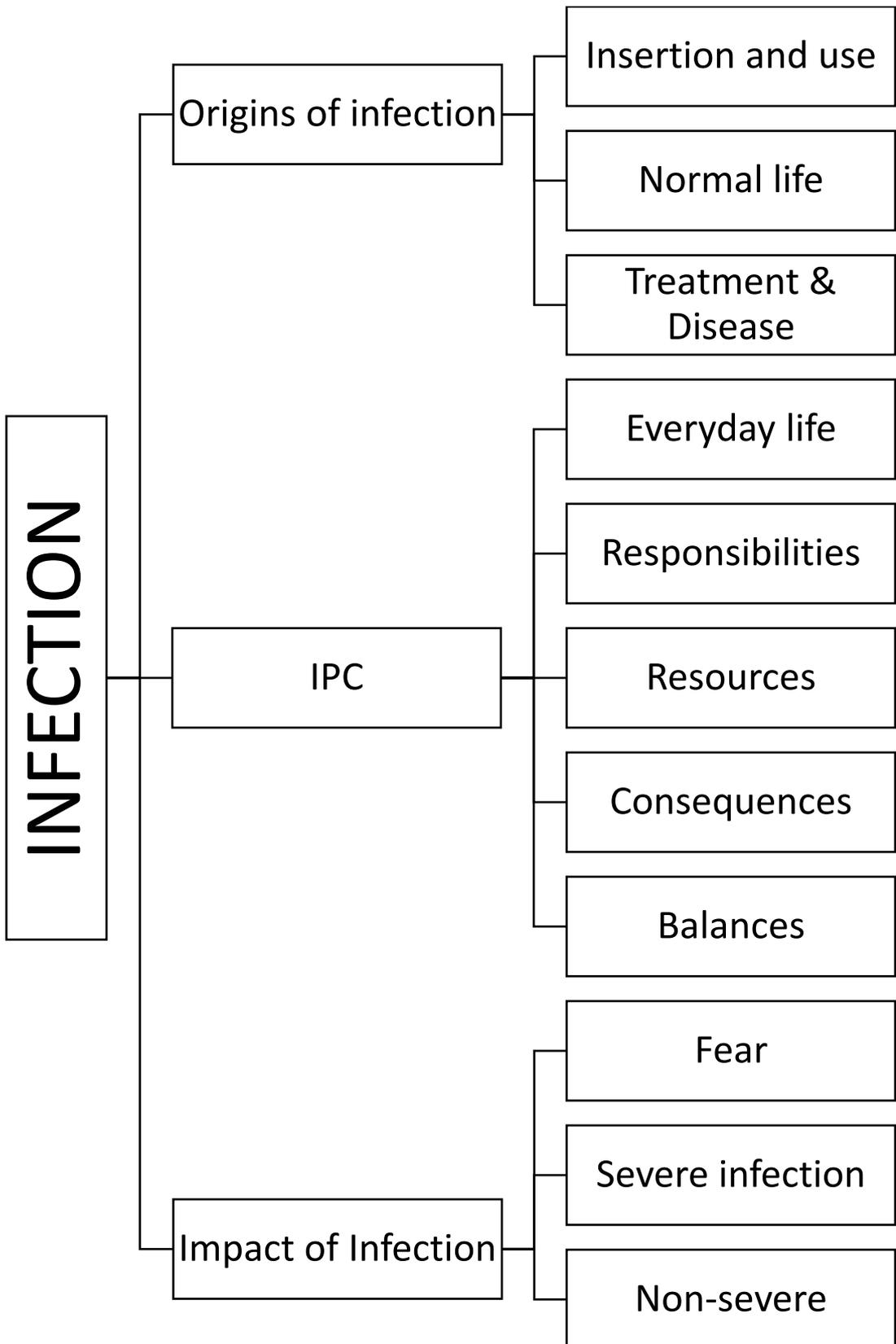


9.5.2 Early coding tree



9.5.3 Further expansion of coding tree





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